

# EVIDENCE REVIEW

## **To inform the development of National Standards for Homecare and Support Services in Ireland**

May 2022



## About the Health Information and Quality Authority

The Health Information and Quality Authority (HIQA) is an independent statutory authority established to promote safety and quality in the provision of health and social care services for the benefit of the health and welfare of the public.

HIQA's mandate to date extends across a wide range of public, private and voluntary sector services. Reporting to the Minister for Health and engaging with the Minister for Children, Equality, Disability, Integration and Youth, HIQA has responsibility for the following:

- **Setting standards for health and social care services** — Developing person-centred standards and guidance, based on evidence and international best practice, for health and social care services in Ireland.
- **Regulating social care services** — The Chief Inspector within HIQA is responsible for registering and inspecting residential services for older people and people with a disability, and children's special care units.
- **Regulating health services** — Regulating medical exposure to ionising radiation.
- **Monitoring services** — Monitoring the safety and quality of health services and children's social services, and investigating as necessary serious concerns about the health and welfare of people who use these services.
- **Health technology assessment** — Evaluating the clinical and cost-effectiveness of health programmes, policies, medicines, medical equipment, diagnostic and surgical techniques, health promotion and protection activities, and providing advice to enable the best use of resources and the best outcomes for people who use our health service.
- **Health information** — Advising on the efficient and secure collection and sharing of health information, setting standards, evaluating information resources and publishing information on the delivery and performance of Ireland's health and social care services.
- **National Care Experience Programme** — Carrying out national service-user experience surveys across a range of health services, in conjunction with the Department of Health and the Health Service Executive (HSE).

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## **Executive summary**



## Executive Summary

### Introduction

The Health Information and Quality Authority (HIQA) is the statutory body established under the Health Act 2007 to drive high-quality and safe care for people using our health and social care services. One of HIQA's many functions is to set standards for health and social care services.

It is well accepted that the preferred place of care for many people is in their own homes, for as long as is possible.<sup>(1)</sup> Care and treatment of complex medical conditions that traditionally occurred in hospital is increasingly being provided at home. In addition, research in current services for older persons suggests an over-reliance on long-term residential care and a lack of intermediate models of care. The future demographic challenges, trends towards increasingly complex care being provided in the home, and the need to focus on a human rights-based approach that facilitates autonomy and choice, underline the need to develop alternatives to meet the needs of the population, including homecare, assisted living and day care. These choices have the potential to allow people to remain in their own homes for longer and also have added protections in the context of prevention of infection.

Homecare and support services were traditionally referred to as 'home help' and 'homecare packages' in Ireland, but in 2018 these services were combined by the Health Service Executive (HSE) to become known as 'home support services.' In addition, the terms 'homecare' and 'home support' are used interchangeably throughout the literature, both nationally and internationally. For the purpose of this review, these terms will be used according to their use in the published literature under discussion.

HIQA recognises the importance of the quality and safety of homecare and support services to support people to remain in their own homes for longer and therefore is developing National Standards for Homecare and Support Services in Ireland, underpinned by this evidence review. These standards will form part of a regulatory framework for homecare and support services in Ireland, currently being developed by the Department of Health. HIQA will work closely with the Department of Health to support this regulatory process, as well as engaging more widely with stakeholders in the development of the National Standards.

The Programme for Government (2020) commits to the introduction of a statutory scheme to support people to live in their own homes by providing access to high-quality, regulated homecare.

At the time of writing this review, the Government is in the process of developing a comprehensive regulatory framework to regulate home support services in Ireland.

In 2021, the Government gave approval to draft a General Scheme and Heads of a Bill to establish a licensing framework for home support providers.

A regulatory framework underpinned by legislation will offer assurance that people using homecare and support services will receive safe, quality, and person-centred care and help address concerns relating to quality-assurance, accountability, training and skills.

It is intended that the scheme will provide equitable access to high-quality services, based on a person's assessed care needs. The importance of integrated care pathways, communication and coordination of care between services to enable people to get the right care, at the right time and in the right place is fundamental to person-centred care. Strong and effective governance arrangements are required at national, regional and local service-delivery level to ensure that people using homecare and support services receive consistent coordinated care. Systems and structures to support collaborative working and communication between homecare and support services and other health and social care services are required, to ensure that people get the integrated care and support they need. The Draft National Standards for Homecare and Support Services will complement and support such arrangements to be implemented in practice. The proposed statutory scheme, together with national standards, will provide a system-wide approach to addressing homecare and support in Ireland.

The expectation is that all services will work to achieve compliance with a set of national standards that provide a framework for best practice in providing person-centred homecare and support, with a focus on achieving the best outcomes for the person using these services.

Alignment of national legislation, policy and standards is required for the protection of all people using homecare and support services. A dynamic service which recognises the value of the workforce and the opportunities of assistive technology will ensure a responsive service, focused on the outcomes of those receiving care and support at home.

The Draft National Standards for Homecare and Support Services will be set out according to the principles outlined in the Standards Development Framework, which was published in September 2021.<sup>(2)</sup> These principles are:

- a human rights-based approach
- safety and wellbeing
- responsiveness
- accountability.

The aim of this review is to provide the evidence base to inform the development of the National Standards for Homecare and Support Services. This evidence is drawn from:

- an overview of homecare and support services in Ireland
- an international review of homecare and support services in seven jurisdictions
- an evidence synthesis of national and international literature which sought to identify characteristics of good person-centred practices in homecare and support services, where people experience safe, high-quality outcomes from the care and support they receive in their home.

The findings are presented in the above order.

## Overview of the Irish context

This section sets out a review of homecare and support services in Ireland at present; this includes a description of the current model for homecare in Ireland, an overview of legislation and policy, and a review of outcome data. This review of homecare and support in Ireland was informed by academic papers, authoritative national websites, annual reports and statistical reports from key organisations, alongside collaboration with experts in this area.

The main findings from this review of services in Ireland are summarised as follows:

### Legislative context

- There is currently no legislation or statutory regulations underpinning the homecare and support sector in Ireland. There is a need for regulatory reform to ensure delivery of care that meets the needs of the Irish population.

### Drivers for improvement

- The current homecare and support sector is largely reliant on informal carers providing care to people to live in their own homes.
- The Sláintecare (2017) report outlines recommendations related to social care expansion, including universal access to homecare.
- HIQA published a position paper on the regulation of homecare in 2021. In it HIQA advocated that homecare services need to be needs led, integrated,

and inclusive of complex care. Age or disability status should not be a barrier or gatekeeper to access homecare and support services.

- Homecare and support services should support enablement and independence, ensuring the dignity and human rights of people are protected.
- Homecare and support services should be person centred, focused on quality and on the outcomes important to those receiving the service.

### **Models of care and integration**

- While homecare and support services are allocated based on need and availability of resources, rather than the individual's ability to pay, there is high demand for services and waiting lists remain.
- National HSE guidelines and service specifications for tenders to provide home support services are already in place for older persons.
- Despite this, inconsistencies remain in home support services for adults (including older persons and people with disabilities), including funding arrangements, assessment of need, eligibility criteria and allocation of resources.
- Variation is also evident in homecare and support services for children with complex needs in our communities.
- Information and Communications Technology (ICT) has a critical role to play in ensuring that information to drive quality and safety in health and social care settings is available when and where it is required.

### **Workforce**

- Home support in Ireland is provided by staff employed by the HSE, voluntary organisations and for-profit organisations.
- There is limited information about the total number of carers employed in Ireland.
- It is widely acknowledged that the sector is challenged by staff recruitment and retention.

The primary goal of homecare and support services in Ireland is to facilitate people to live in their own homes as independently as possible, for as long as possible, if they wish to do so. There is currently no legislation or statutory regulations underpinning the homecare and support sector in Ireland. There have been long-standing calls for the introduction of legislation to support and safeguard people using homecare and support services in Ireland from successive governments, researchers and advocacy groups. In addition, the current homecare and support sector is largely reliant on informal carers providing care to people to live in their own homes.<sup>(3)</sup>

## Models of care and integration

Publicly-funded homecare and support in Ireland is available free of charge, is not means tested and no contributions are required by the person using the service. However, as homecare and support services are allocated based on need and availability of resources rather than ability to pay, the provision of homecare and support by the state is subject to available funding and hence waiting lists are evident.

Publicly-funded home support services are funded by the State through budgets allocated annually to the Health Service Executive (HSE). These home support services are then either provided by staff directly employed by the HSE or by voluntary (not-for-profit) or private (for-profit) providers who are funded by the HSE to provide services through a tendering process. Individuals may also purchase home support services directly from private providers operating independently in the open market. The HSE has no oversight of these privately-funded services.

Access to publicly-funded homecare and support in Ireland is based on assessed need. An assessment of need is conducted to explore the needs of the person and appropriate supports required. National guidelines and service specifications for tenders to provide home support services are already in place for older persons. Notwithstanding this, the literature highlights inconsistencies which remain in home support services for adults (including older persons and people with disabilities), including funding arrangements, assessment of need, eligibility criteria and allocation of resources.

Inconsistencies are also evident in homecare and support services for children with complex needs in our communities. Reform of homecare and support services in Ireland presents an opportunity to establish a framework for best practice in providing person-centred homecare and support, without age restrictions, with a focus on achieving the best outcomes for all people using these services.

## Workforce

Home support in Ireland is provided by staff employed by the HSE, voluntary organisations and for-profit organisations. Currently, outside of the HSE, little is known about home support workers in Ireland, including the total number of carers employed.<sup>(4)</sup> Home support workers in Ireland are not required to register with a professional health and social care registration body. It is widely acknowledged that the sector is challenged by staff recruitment and retention.<sup>(4)</sup> There have been calls to the Irish government for a comprehensive workforce review in social care in order

to address the current recruitment and retention challenges and the increase in demand for homecare and support.

### **Information and Communications Technology (ICT)**

Information and Communications Technology (ICT) has a critical role to play in ensuring that information to drive quality and safety in health and social care settings is available when and where it is required. However, a review by HIQA of ICT enablement of older persons services in Ireland<sup>(5)</sup> shows that the current ICT infrastructure in Ireland's health and social care sector is highly fragmented, with major gaps and silos of information which prevents the safe, effective transfer of information. This review demonstrates a clear and pressing need to develop a coherent and integrated approach to health information, based on standards and international best practice.

### **Drivers for improvement**

It is evident from the array of published literature and reports that Ireland is deeply committed to improving homecare and support services. Research has been conducted by subject matter experts from government departments, State bodies, Irish universities, advocacy groups and public, private and voluntary homecare and support providers, all of whom share common recommendations that Ireland needs legislation to underpin the provision of quality homecare and support. The ten-year strategic framework set out in Sláintecare aims to "make it possible for people to stay healthy in their homes and communities for as long as possible, receiving the Right care, in the Right place, at the Right time, delivered by the Right team"<sup>(6)</sup> The Sláintecare (2017) report outlines Sláintecare's recommendations related to social care expansion, including universal access to homecare.<sup>(7)</sup>

### **Proposals for a regulatory framework**

HIQA published a report on *The Need for Regulatory Reform* in 2021<sup>(8)</sup> that summarises HIQA's experience of regulating social care services and outlines why change is needed to make regulation fit-for-purpose into the future. The report outlines the challenges currently faced by the homecare sector; for example, the lack of statutory entitlement to formal homecare and the current variation in access to homecare services. Emphasis is placed on the need for investment in regulatory reform to ensure the capacity and capability to deliver care that meets the needs of the Irish population.<sup>(8)</sup> The report also states that the provision of good quality homecare should be a key component of any future social care system. HIQA subsequently published a report on *Regulation of Homecare: A Position Paper* that sets out HIQA's position on the future of regulating homecare services in Ireland.<sup>(9)</sup>

This report was published in conjunction with a review of the current homecare landscape both nationally and internationally entitled *Regulation of Homecare: Research Report*.<sup>(1)</sup> Based on the evidence, HIQA recommended priority areas for the regulation of homecare services in Ireland in the position paper as follows:

- be inclusive to all who are in receipt of formal homecare
- improve the performance and quality of homecare
- provide assurance to people receiving homecare and the public that minimally acceptable standards are achieved
- provide accountability on both performance and value for money.<sup>(9)</sup>

HIQA has strongly advocated for a complete review and, where necessary, an overhaul of the homecare sector. HIQA also strongly advocated that homecare services need to be integrated and needs led, removal of any barrier to access (such as age), and services that support enablement and independence to be accounted for, ensuring the human rights of people in receipt of homecare are protected. HIQA highlighted that while it is up to the Government to decide if more complex aspects of care will be included in the regulation of homecare, it should consider that health and social care services intersect frequently and are often integrated, and there is a strong argument that this will increase over the coming years with the move to more care in the community at the heart of the Sláintecare ethos.<sup>(9)</sup>

A statutory entitlement to homecare and support services would help to address the current inequities in service delivery. It is envisaged that the implementation of national standards underpinned by legislation and regulations will also reduce variation in practice and promote quality person-centred care.

## **International Review of homecare and support services in seven countries**

This section describes the international models and arrangements for homecare and support services, relevant legislation, policy, standards and available outcome data. The international context and lessons to inform the development of draft standards in Ireland are outlined. In addition, as part of its international review, HIQA engaged with key stakeholders in international jurisdictions.

The core messages from the international review can be summarised as follows:

### **Legislation and policy**

- There is a need for a standardised definition of what is meant by homecare and home support and what it constitutes to ensure clarity of scope, so that it can be adopted consistently across all Irish health and social care services.
- Standards should be aligned with legislation and regulations, but standards can also offer 'stretch goals' for quality improvement over-and-above the regulations.
- Clear governance structures are required to ensure corporate and clinical oversight and accountability.

### **Standards and regulations for homecare and support services**

- The scope of the standards should be clear and all relevant services should be included within the scope.
- The standards and the system of regulation need to be attainable, in order not to exclude smaller providers.

### **Outcomes**

- Homecare standards should be outcome based, person centred and make sense to both provider organisations and individual service users.
- In addition to being outcomes focused and person centred, standards should be holistic in approach and consider the social and emotional wellbeing as well as the physical wellbeing of the service user.

### **Eligibility**

- The service provided should be based on assessed needs, rather than the person's diagnosed condition(s).
- A focus on equity and accessibility (for example, minority groups) within the standards is recommended.
- Eligibility criteria for services should be clear and transparent, with a standardised, transparent assessment process, which is easy to navigate.

- All the jurisdictions reviewed noted that homecare and support services have fragmented into three key areas of delivery: older people; adults with disability; and children.

### **Partnership**

- Service users, their families and providers are equal and key partners in the development and implementation phases of standards and should also be included in assessment of organisational performance against those standards.

### **Facilitation of implementation**

- There is a need to incorporate lead-in time for implementation of standards.
- Provider organisations require significant levels of support to implement standards and provide appropriate evidence of attainment of those standards.

### **Workforce**

- The workforce is central to the delivery of high quality, person-centred homecare and support services. Any standards for this service must include consideration of the need to grow and develop this workforce.
- A number of countries have introduced registration of care workers, training and pathways for career progression, facilitating professionalisation and delivery of increasingly complex care.

An international review of homecare and support services in the following seven countries was conducted to inform the standards:

- Scotland
- England
- Northern Ireland
- Wales
- The Netherlands
- New Zealand
- Australia.

These seven jurisdictions were chosen following feedback from the scoping consultation, findings from the evidence synthesis and input from key stakeholders. A further desktop review, involving web-based searches of relevant literature and websites, identified a number of key organisations and experts to contact and engage with. The international review includes a review of information from authoritative international websites, national reviews, annual reports and statistical

reports from key organisations, academic papers and videoconferences with international experts in this area from Ministries of Health, standards development teams and health and social care regulators.

All of the countries reviewed are exploring how to move from a regulatory environment that focuses primarily on organisational processes to one that focuses instead on user-led outcomes, placing the service user at the centre of all aspects of homecare services. The evidence shows that each jurisdiction has legislation, strategy, policy, and service delivery systems in place for homecare and support services. The main findings and learning from the international jurisdictions are as follows.

### **Legislation and policy for home support services and increasing complexity and need**

In all of the countries included, there was clear government policy, through strategy and framework documents, to support people to remain cared for in their own homes for as long as possible. Like Ireland, there was also a reliance on informal carers in all countries studied. The majority of this legislation includes, either in primary legislation or associated statutory guidance, clearly-defined boundaries for homecare and support or provides examples of what tasks are included in these services. A key message from other jurisdictions is to streamline the legislative context for homecare wherever possible and to ensure that the rationale for any standards are made explicit, in order to assist providers to demonstrate compliance with legislation and associated regulations.

Home support services were referred to by a variety of terms in the seven countries included in this review. For example, the following terms were used: home support, care at home, domiciliary care, homecare and home help. Even within some countries, more than one term is used. This lack of a standardised definition and interpretation can lead to challenges in what is meant by home support services at a local delivery level, for example between trusts or local authorities. Therefore there is a need to develop a standardised definition and ensure clarity of scope of what is meant by homecare and home support and what it constitutes, so that it can be adopted consistently across all Irish health and social care services.

### **Standards and regulations for home support services**

Northern Ireland was the only country out of the seven countries studied that had a dedicated mandatory set of standards specifically for homecare. These standards form an integral part of activities to regulate, inspect and monitor domiciliary care services. The National Institute for Health and Care Excellence (NICE) *Home care for*

*older people* quality standard applies to England and Wales, but these standards are not mandatory or enforceable. The remaining countries had overarching standards that apply either to all health and social care services (Scotland and New Zealand) or all older person's services (Aged care Australia) or all disability services (National Disability Insurance Scheme Australia).

All countries reviewed, with the exception of New Zealand, have regulations related to homecare in place. All countries include personal care (activities of daily living) within these regulations. Personal support activities or instrumental activities of daily living (IADL) are included under regulations in Scotland, Australia and the Netherlands. In England and Wales, services that provide personal support activities (IADL) only are not regulated. However, if a service is regulated to provide personal care, personal support services will be reviewed during inspection. At interview with the Care Quality Commission in England and the Care Inspectorate in Wales, both recommended that both personal care and personal support should be included within regulations, in order to ensure services are more person centred and focused on the needs of the person and to eliminate any grey areas in regulation.

Interviewees also recommended that nursing care should be included in the scope of standards and regulations for homecare, especially as homecare becomes increasingly complex, and that it may be restrictive to exclude this aspect of care and support. In addition, interviewees recommended that while standards should align with regulations, they should also offer 'stretch goals' for quality improvement over-and-above the regulations.

### **Age related services and eligibility**

While homecare and support is generally associated primarily with services designed to support older people, in all seven jurisdictions reviewed, homecare and support services also provided support to adults aged 18 to 65 years and to children and young adults. There is, however, significant variation within each jurisdiction reviewed in respect of how services to support children are regulated and quality assured.

All the jurisdictions reviewed noted that homecare and support services have fragmented into three key areas of delivery: older people; adults with disability; and children. This fragmentation is reflected in complex regulatory and monitoring arrangements.

It must be noted that increased specialisation of this nature is often considered a powerful driver for improvement in the quality of care delivered. However, for service users, this categorisation is often perceived as an organisational or

administrative convenience that does not always make sense to the person using the service and their family. Additionally, significant resources are required to assist service users to transition from one service area to another, such as children moving from Children's Services to Adult Services and to manage risks associated with moving out of one support system and into another.

It may be important to consider whether having very defined age limits or brackets for homecare and support services could actually present barriers to access, or contribute to increased risk of service failure at points of transition from one category to another.

### **A focus on service user outcomes in monitoring home support services**

A number of countries included in this review had a strong focus on service-user outcomes in their monitoring and regulation of homecare and support services. A good example of this can be seen in Wales, where in the past, regulations, standards and inspection methodologies brought in under the Care Standards Act 2000 were criticised for a focus on the various operational and governance processes characteristic of a well-run organisation, rather than user-based outcome measures. Domiciliary care is now regulated by the Care Inspectorate Wales against a regulatory framework put in place under the Regulation and Inspection of Social Care (Wales) Act 2016. This has changed the way that services are registered and inspected, with a focus on wellbeing outcomes for people using services and improving quality of care and support. This transition provides valuable learning to Ireland in terms of its development of regulations and associated standards for homecare and support services, which focus on the outcomes important to people using the service.

Additionally, in Scotland, the Quality Frameworks against which the Care Inspectorate monitors and inspects home support services adopts an outcomes-focused approach, where a holistic view of the person receiving care and support is emphasised.

In Wales, New Zealand, Australia, the Netherlands and England, approaches to person-centred, outcome-focused assessment of need, care planning and evaluation are enshrined in legislation, for example the Care Act 2014 (England); Social Services and Wellbeing (Wales) Act 2014; and the Health and Disability Services (Safety) Act in 2001 in New Zealand.

Other jurisdictions include a strong focus on individual as well as clinical outcomes for users, for example the Dutch Institute for Accreditation. In Australia, the Home

Care Common Standards (2018) have been effective in driving change towards an outcomes-based system of accountability.

Having such a focus may ensure that inspections of homecare and support services are not restricted to a compliance versus non-compliance approach, which may result in some aspects of care and support delivery, such as the person's wellbeing and quality of life, being overlooked as indicators of how well the service is performing. Furthermore, an outcomes-focused approach may highlight the importance of the person's voice in the inspection process and establishing what outcomes are most important to them. As a result, it would be useful for the development of inspection frameworks to involve consultation with people experienced in delivering and receiving care at home.

A focus on outcomes reflects a more general move towards citizen participation, empowerment and personalisation of service design and delivery, and therefore of new standards for the service. It also provides opportunities to involve the service user and or their families in the assessment of the quality of the service they are receiving. A number of countries such as the Netherlands, Australia and New Zealand already include the service user and or their families in the monitoring and evaluation process, with other jurisdictions for example, Scotland and Northern Ireland actively seeking ways to do so.

Models are emerging of how this shift can be achieved, including in Wales, New Zealand, Australia and the Netherlands. However, it should be noted that each of these jurisdictions also noted the considerable challenges in translating broad principles of independence, participation and customisation into practice.

### **Eligibility for home support services and assessment of need**

In all of the countries studied, eligibility for home support services was primarily based on the care and support needs of the person. All countries, except the Netherlands, include an assessment of the person's finances when determining their eligibility for free or part-subsidised care and support.

It is important that all potential recipients of homecare can be assessed using the same criteria. The adoption and full implementation of a standardised tool for assessment offers a consistent and comprehensive approach to assessment and thus will reduce the likelihood of variation and risks in care delivery. Assessments of care needs should place the care recipient at the centre of the process and should also incorporate the views of their family or representatives, as well as their community and primary caregivers. These assessments should be subject to regular review, to identify and respond to people's changing care needs as they emerge.

## **Commissioning and funding models**

All jurisdictions reviewed reported that funding structures to deliver homecare and support services appear complex and piecemeal. Elements making up the funding streams range from central government allocations, general taxation, mandatory social insurance (for example, in the Netherlands), local government funding and personal contributions. This complex web of funding can be confusing, not only for prospective service users, but also for provider organisations who must meet contractual reporting and monitoring requirements for a range of funders, in relation to activity and various quality indicators.

A single standard or suite of standards for care and support at home has the potential significant benefit of delivering a single, coherent, comprehensive governance structure, agreed management data returns and quality measures that meet the requirements of all funders, in addition to the needs of the population.

## **Partnership Working**

All countries interviewed noted that not only are they moving to a more outcomes-based, personalised approach to the development and application of standards, they are also considering how provider organisations are included in the process of developing and monitoring the standards themselves. Mechanisms for this vary, with the Home and Community Health Association in New Zealand, which engages with the New Zealand government to establish, promote and recognise high standards of practice, perhaps the most well established.

Across jurisdictions, interviewees also commented on the importance of co-working with provider organisations through the standards development process and in the provision of tools to support providers to implement the final standards in their own organisations.

## **Integration, Accessibility and Proportionality**

Interviewees noted that as services move to a more outcomes and person-centred model of delivery, there are significant opportunities through the design and development of standards to promote closer integration between different aspects of support to people in their own homes: for example, general practitioner (GP) services; acute care; and community care.

All interviewees reported working in complex systems, with every jurisdiction reporting significant variation, not only in the characteristics of those using the service, but also in the composition of provider organisations seeking to deliver high-quality care and support. These organisations can range from one or two people

coming together to support an individual, to large multinational companies. Interviewees noted that the standards must be easy to apply to organisations of any size or complexity.

Interviewees also emphasised the importance, not only of clarity and consistency in the application of standards, but of adopting a proportionate approach to the level and nature of management data and user feedback required to demonstrate compliance with the standard. Similarly, if standards are to provide assurance and inspire confidence in users and their families, they should be designed and written in ways that make sense to individuals and families, not just providers, commissioning bodies and or regulators.

Alongside that, many interviewees noted the importance of reducing unnecessary demands on providers, while maintaining high levels of compliance and quality assurance, as a challenging but necessary task.

## **Communication**

Interviewees noted that homecare and support providers are uniquely placed to identify potential deterioration or changes in respect of a person's health and wellbeing at an early stage. Appropriate communication with the user and or their family, the GP or lead health and social care professional and the commissioning organisation is central in promoting and maintaining levels of wellbeing, and standards should reflect the importance of timely communication.

There was some variation across the countries interviewed in how and when core information about the service-user, their needs, aspirations, preferences and desired outcomes are communicated with provider organisations: for example, in the UK providers are given a list of tasks to be carried out, whereas in the Netherlands providers have access to a full comprehensive assessment, enabling full participation by the user in the design of the plan for delivery of their care and support.

Communication is therefore recognised by all countries interviewed as a key element of any standard, whether with the user, provider, healthcare professional or commissioner of the care.

## **Barriers to implementation**

All seven respondents noted that there are some key challenges that arise in the introduction of standards for homecare and support services.

All interviewees noted that the 'market' of homecare and support providers is perceived as fragile, with different levels of provider-maturity posing risks that any

additional reporting requirements may either be unachievable or too onerous for providers to complete. There was a sense that, if regulation and standards are fragmented across user-categories, then some providers may choose to restrict their activity to the sector that is not yet regulated, or where it is perceived that the standards are 'easier' to attain, thereby creating a risk of unintended consequences.

As noted elsewhere, homecare and support services are delivered in a complex network of funding and commissioning arrangements. It is important that there is consistency of approach by all parties involved so that providers have, wherever possible, a single set of quality standards and monitoring returns.

Finally, interviewees all reported that implementation of new or revised standards is resource intensive for regulators and providers alike and that realistic levels of support for providers and users need to be built-in to any implementation schedule.

### **Factors that facilitate implementation**

Interviewees advised that there were a number of factors that can assist and expedite successful implementation of standards. System leadership by the regulator or inspecting authority was seen as perhaps the most important factor. This can manifest in many different ways, including: consistency of approach; clarity of expectations; design and delivery of implementation support tools and worked examples; and flexibility in assessing and validating evidence of compliance.

All interviewees noted the importance of working with providers and users to both co-produce the standards and to develop innovative ways of assessing evidence. For example, the Netherlands regularly audits user experiences and also requires providers to submit core performance and activity data on an annual basis.

Colleagues in Australia strongly advocated a phased approach to introduction of standards, and are moving forward on a state-by-state or geographical basis. While acknowledging that this could mean a significant delay for some providers and service users, their experience suggested that implementation is very resource intensive and a modular approach was ultimately more effective.

### **Workforce**

Respondents were unanimous in noting that homecare is a human service, delivered to people by people. The imperative of moving away from a process-focused to person-focused approach to standards is recognised as placing increasing emphasis on ensuring that the workforce is properly equipped to deliver high-quality care and support services to people in their own homes.

Every jurisdiction noted similar challenges in relation to recruitment, retention and remuneration of the workforce. All noted the importance of developing not only the status of homecare and support work, but of upskilling the workforce to deliver increasingly complex care at home, with Northern Ireland perhaps the most advanced jurisdiction in respect of both regulation and mandatory training arrangements.

In four of the countries studied (Scotland, Wales, Northern Ireland and the Netherlands), it is compulsory for home support workers to register with a professional body.

In England there are currently no formal requirements for registration of staff working in home support services but there are minimum qualification requirements for general domiciliary care staff. Similarly, home support workers are unregulated in New Zealand but are accountable under the Health and Disability Commissioner Act 1994 and must adhere to the Code of Health and Disability Services Consumers' Rights. In addition, the New Zealand government has enacted legislation to address challenges and has placed duties on the sector to value workers as a central part of the health system.

A lesson that can be drawn from these countries is the emphasis that is placed on the role of the social care workforce, recognising their contribution to society, and seeking to improve retention through improved working conditions and wages. The need to develop the social care workforce, providing ongoing education and training was also supported internationally.

## Findings from the evidence synthesis

The aim of the evidence synthesis was to assess and appraise available evidence to identify characteristics of good person-centred practices in homecare and support services, where people experience safe, high-quality care and support at home. To achieve this, a systematic search of academic databases and grey literature repositories was conducted. All articles were screened for inclusion and a quality appraisal conducted of all included articles. Articles were then described and critically evaluated to identify emerging themes.

As previously stated, the Draft National Standards for Homecare and Support Services will be set out according to the following principles:

- a human rights-based approach
- safety and wellbeing
- responsiveness
- accountability.

Accordingly, the findings from the evidence synthesis are structured under these principles and are summarised below.

### **Human Rights-based approach**

- Dignity and respect are central to providing person-centred care.
- A client's involvement is at the core of a successful homecare service.
- Providers should maintain effective communications and relationships with people using services and their families or informal carers to contribute to improvements in practice.

### **Safety and wellbeing**

- The *National Standards for Adult Safeguarding* and the National Guidance on Guidance on a Human Rights-based Approach in Health and Social Care Services should underpin all health and social care services, including those provided in a person's home.
- Person-centred homecare services should meet the needs of the person in a holistic way, and not be overly restricted by task-oriented care plans or issues with timing.
- The safety of the person in their home can be supported by being aware of signs of decline in a person's mental wellbeing and focusing on preventative measures to reduce risk of acute illness or injury.

### **Responsiveness**

- Homecare services should include competent health and social care staff, who are skilled and who collaborate and communicate openly with families and people receiving care, to bring about the best possible outcomes.

- Health and social care staff should have enough time to carry out holistic, person-centred visits and should be able to time their visits around the schedule of the person and their families.

#### **Accountability**

- For people using services, an effective, high-quality service ensures consistency and continuity of care and support to individual service users.

#### **Implementation**

- There is a need to develop tools to support implementation of homecare standards, for example, webinars, podcasts, case studies and learning materials.

#### **Economics of homecare**

- Multiple national and international reports predict a significant increase in the demand for home support in the coming years, largely due to an ageing population. These reports recommend investment in strategies for early intervention of homecare and support services.

#### **Telehealth**

- In homecare and support services, telehealth may facilitate everyday tasks, improve service-users' safety, and decrease the informal caregiver burden.
- Telehealth may offer an opportunity to help address issues and challenges in the homecare and support sector.

## **Human rights-based approach**

Applying the principle of a human rights-based approach (HRBA) in a homecare and support setting means that services respect, protect and promote the human rights of the person receiving care and support at all times. Human rights are rights that all people should enjoy and are protected by a legal framework and human rights treaties, which Ireland has agreed to uphold. These include the European Convention on Human Rights Act 2003, the United Nations Convention on the Rights of Disabled People 2006 and the Charter of Fundamental Rights of the European Union 2000.

The *National Standards for Adult Safeguarding* and the National Guidance on Guidance on a Human Rights-based Approach in Health and Social Care Services should underpin all health and social care services, including those provided in a person's home.

The majority of studies reviewed as part of the evidence synthesis considered different aspects of the experience of users, rather than providers of homecare and

support services. The studies provide important insights for organisations and for regulators who seek to provide a human rights-based approach to care and support at home.

A human rights-based approach in homecare and support services emerged from the literature under the themes of 'Dignity and Respect', 'Autonomy', 'Participation', 'Equality' and 'Communication'. The key insights for the development of standards for homecare and support services are:

- Dignity and respect are central to providing person-centred care. Homecare and support providers need to accept and acknowledge the values and preferences of a person.
- A person's life story, knowledge and experiences need to be acknowledged and respected in the design and delivery of care and support services.
- A client's involvement is at the core of a successful homecare service. Supporting a person to make choices and decisions should form an integral component of the service delivery. Homecare and support providers should demonstrate how they will determine the extent to which a person wishes to be involved as a partner in their own care and to make their own care choices. The culture of homecare and support needs to reflect this partnership approach and ensure that the client's knowledge, values, skills and cultures are included in their care and support plans.
- Providers should maintain effective communications and relationships with people using services and their families or informal carers to contribute to improvements in practice.
- Strategies that have worked well for family carers include conflict resolution, organising care by family, friends and neighbours and establishing support groups.
- Homecare and support providers should promote equity for all people using homecare services regardless of: age; civil status; disability; family status; gender; membership of the Traveller community; sexual orientation or religion; race, colour or nationality.
- Providers should provide training to staff in effective communication skills to foster an increased sense of security and wellbeing for service users.

## **Safety and wellbeing**

The principle of safety and wellbeing examines how homecare and support services work to protect and enhance the safety and wellbeing of people who use their services. Safety and wellbeing as a principle relates to safeguarding, the prevention of harm, and the comfort of a person while they are accessing health and social care

services. It emphasises the importance of the experience of a person using services, and encourages health and social care staff to see the whole person, rather than focusing solely on their identified medical or social care needs.

Safety and wellbeing in homecare and support services emerged from the literature under the themes of 'quality of life and experiences' and 'safety.' Further examination of the theme 'quality of life and experiences' revealed the sub-themes 'maintaining the home environment,' 'social connectedness' and 'meeting people's needs in a holistic way.' The key insights for the development of standards for homecare and support services are:

- Characteristics of good person-centred care delivered in the home emerged as respecting the home of the person and ensuring minimal disruption to this environment, where good memories and experiences are not replaced by memories of being unwell, or feeling unsafe.
- The ability to remain connected to neighbours, friends and family has a positive impact on both a person's safety in their home and their overall wellbeing, and people should be supported to remain active in their communities where this is possible.
- Good, person-centred homecare services should meet the needs of the person in a holistic way, and not be overly restricted by task-oriented care plans or issues with timing.
- Lastly, it emerged that the safety of the person in their home can be supported by preventing loneliness, being aware of signs of decline in a person's mental wellbeing, and focusing on preventative measures to reduce risk of acute illness or injury.

## **Responsiveness**

The principle of responsiveness includes both how homecare and support services are organised to deliver coordinated care and support that meets the needs of people using their service, and how people working in these services identify, assess and respond to a person's needs in day-to-day practice.

The principle of responsiveness emerged from the literature under the key themes of 'professional duty and competence', 'communication' and 'collaboration'. The key insights for the development of standards for homecare and support services are:

- Characteristics of responsive homecare services include competent health and social care staff, who are skilled and who collaborate and communicate openly with families and people receiving care, to bring about the best possible outcomes.

- Responsive health and social care staff should have enough time to carry out holistic, person-centred visits and should be able to time their visits around the schedule of the person and their families.
- Collaboration and good communication emerged as important characteristics of responsive homecare and support services, where these can support continuity of care and homecare worker job satisfaction when the appropriate processes are in place.
- The expectations of the person receiving care and their families should be respected, where both parties have an awareness of what a responsive homecare service can and cannot do. Homecare workers should be supported by their organisation to safely meet the expectations of service-users and families.

## Accountability

The principle of accountability is the foundation for homecare and support services to ensure that people receive high-quality safe care and support that is consistent, coordinated and focused on achieving good outcomes for them. Accountable organisations have a clear vision for their work, support their staff to deliver this vision, are focused on the service user and work well with other relevant services, as well as family members or unpaid carers.

The principle of accountability emerged from the literature under the key themes of 'leadership and governance', 'collaboration' and 'integration' between homecare, and health and social care services, 'quality of care' provided and 'sustainability'.

The key insights for the development of standards for homecare and support services are:

- A client's involvement is at the core of a successful homecare service. An accountable provider of homecare services involves users in decision-making, supports service user autonomy and dignity, and facilitates users and their families or carers to exert control over their own care and support.
- For service users, an effective, high-quality and therefore accountable homecare service ensures consistency and continuity of care and support to individual service users. This requires accountable providers to plan and organise resources, including their workforce and financial resources, to take account of the needs of service users. Accountable providers will also implement work schedules and models of care that facilitate flexibility of care delivery and also improve workforce retention.
- Homecare and support services are delivered by individual workers to individual service users. An accountable provider will seek to develop a

culture of delivery of high quality care, through motivating, supporting and developing their workforce. This includes ensuring that staff have the necessary knowledge and skills to deliver the care and support required by an individual service user.

- Homecare and support services do not operate in isolation. Accountable providers seek to achieve integrated, coordinated and seamless care and support by communicating and collaborating effectively with a range of other services. These include hospitals, primary care providers and other health and social care services, as well as the service user and their families and carers.
- Effective collaboration requires clear and timely communication of key information, both within the organisation and with external partners in the delivery of care. Accountable organisations should put information management systems in place in line with a clear governance framework which are reliable, secure and shared in a timely and appropriate manner.

### **Other findings from academic and grey literature**

As part of the evidence synthesis, additional targeted searching was conducted to look at the areas of implementation, economics of homecare, and telehealth and to present a high level overview of these areas. In-depth systematic literature searching was not conducted for these areas, as this was outside of the scope of this evidence review.

### **Implementation**

In terms of implementation, this targeted review found a scarcity of research pertaining to tailoring implementation strategies. Moreover, there is a lack of research specific to implementing standards for homecare and support. Nonetheless, Ireland can learn from experiences from international standard-setting bodies in developing tools to support implementation of homecare and support standards. For example, the National Institute for Health and Care Excellence (NICE) in the United Kingdom developed and published guidelines on *Home care: delivering personal care and practical support to older people living in their own homes* in 2015. Alongside key stakeholders, NICE identified areas that may pose challenges to the implementation of the guidelines and subsequently suggested changes to overcome these challenges. For example, perceived challenges included providing person-centred care to deliver better quality of life for the person using services and greater job satisfaction for the workforce.<sup>(10, 11)</sup> To overcome these challenges, NICE developed a suite of tools to help services adopt person-centred resources, entitled *Tools to help you put the guidance into practice* and are categorised according to

'education,' 'audit and service improvement' and 'shared learning' and include webinars, podcast, case studies and shared learning.<sup>(12)</sup>

### **Economics of Homecare**

While a review of cost-effectiveness was outside the scope of this evidence review, this section highlights evidence from reviews on national and international financing in homecare. According to the Economic and Social Research Institute (ESRI), Ireland has one of the highest levels of unmet homecare and support needs in Europe.<sup>(4)</sup>

An ESRI report entitled 'Demand for the Statutory Home Support Scheme'<sup>(4)</sup> is the first of three research projects funded by the Department of Health to inform the cost implications of the development of a statutory home support scheme in Ireland. The report estimates the potential demand for home support if a statutory scheme were to be introduced, under various policy scenarios.

According to multiple reports, the success of any statutory homecare and support scheme can be determined by its ability to meet demand for services. Multiple national and international reports predict a significant increase in the demand for home support in the coming years, largely due to an ageing population.<sup>(4, 13-16)</sup> These reports recommend investment in strategies for early intervention of homecare and support services, to reduce costs relating to hospital admissions and the need for longer-term, and more intensive care packages to allow for more complex care to be delivered in the home setting.

### **Telehealth**

The increased demand for homecare and support services call for health reform and cost-saving mechanisms to promote independence and provide complex care for people who need support to live at home.<sup>(17)</sup> In homecare and support services, telehealth may facilitate everyday tasks, improve service users' safety, and decrease the informal caregiver burden. Telehealth may offer an opportunity to help address issues and challenges in the homecare and support sector, such as shortage of skilled staff and increased demand for long-term care.

According to the World Health Organization (WHO), the terms telehealth and telemedicine are synonymous. Telehealth includes interventions that use information communication technologies (ICT), tele monitoring (for example, telemetry devices to capture a specific vital sign, such as blood pressure, glucose, weight or heart rhythm), sensors, electronic health records, assistive devices, e-learning, educational technology, decision support, tracking (to locate people or objects such as GPS trackers) and personal medical records and so on.<sup>(18)</sup>

As outlined, telehealth is used by homecare and support services for a variety of reasons. However, a detailed, in-depth review of the use, effectiveness and cost effectiveness of specific technologies was outside the scope of this evidence review. Nevertheless, it is recognised that the current use of telehealth, along with the potential increased use and demand in the future, will impact on the structure and delivery of homecare services in the future.<sup>(19)</sup> As recommended by HIQA in 2021<sup>(8)</sup> there is a need to undertake an assessment of the effectiveness and cost-effectiveness of health technologies in homecare and support in the Irish context.

## **Conclusions and next steps**

Strong and effective governance arrangements are required at national, regional and local service-delivery level, to ensure that people using homecare and support services receive consistent coordinated care. Systems and structures to support collaborative working and communication between homecare services and other health and social care services are needed, to ensure that people get the integrated care and support they need and that the information required to drive quality and safety is available when and where it is required. Service provision should be based on a standardised assessment of needs.

The learning from the COVID-19 pandemic and best practice internationally will inform the development of evidence-based person-centred standards for homecare and support services in Ireland, which focus on the safety, dignity and wellbeing of the person using the service, enabling them to live in their own homes for as long as possible. Regulations and standards should apply to all homecare and home support services, without restrictions, such as age.

The findings from this evidence review, along with extensive stakeholder engagement and consultation, will inform the development of Draft National Standards for Homecare and Support Services. These standards will promote quality improvement within services by setting out what high-quality and safe homecare and support services for people should look like, and will support and assist service providers to ensure best practice and a quality person-centred service. Following approval by the Board of HIQA, the standards will be submitted to the Minister for Health for approval. The approved standards will be made publicly available on the HIQA website.

## **Introduction**



## 1. Introduction

### 1.1 Background

The Health Information and Quality Authority (HIQA) is the statutory body established under the Health Act 2007 to drive high-quality and safe care for people using health and social care services in Ireland. One of HIQA's many functions is to set standards for health and social care services.

It is well accepted that the preferred place of care for many people is in their own homes, for as long as is possible.<sup>(1)</sup> Care and treatment of complex medical conditions that traditionally occurred in hospital is increasingly being provided at home. In addition, research in current services for older persons suggests an over-reliance on long-term residential care and a lack of intermediate models of care. The future demographic challenges, trends towards increasingly complex care being provided in the home, and the need to focus on a human rights-based approach that facilitates autonomy and choice, underline the need to develop alternatives to meet the needs of the population, including homecare, assisted living and day-care. These choices have the potential to allow people to remain in their own homes for longer and also have added protections in the context of prevention of infection.

HIQA recognises the importance of the quality and safety of health and social care services in Ireland. Having national standards in place allows for a consistent approach to quality improvement. National standards provide a framework for the development and continuous improvement of person-centred, high-quality, safe and effective services. However, a system-wide approach requires policy and legislation to also be in place.

The Programme for Government (2020) has committed to introducing a statutory scheme to support people to live in their own homes for longer.<sup>(20)</sup> The Department of Health is currently developing a new statutory home-support scheme, which aims to provide equitable and transparent access to high-quality services for people, based on their assessed care needs. The Government's aim is to ensure that people using services are safeguarded and protected, and a responsive, person-centred, quality-driven home-support service is provided.

Alignment of national legislation, policy and standards in the area of homecare is required for the protection of people using homecare services. A dynamic service which recognises the value of the workforce and the opportunities of emerging technology will ensure a responsive service, focused on the outcomes of those receiving care at home.

The statutory scheme, together with national standards and service provider policies and procedures, will provide a system-wide approach to addressing homecare in Ireland.

The importance of integrated care pathways, communication and coordination of care between services to enable people to get the right care, at the right time and in the right place is fundamental to person-centred care.

Strong and effective governance arrangements are required at national, regional and local service-delivery level to ensure that people using homecare services receive consistent coordinated care. Systems and structures to support collaborative working and communication between homecare services and other health and social care services are needed, to ensure that people get the care and support they need. The Draft National Standards for Homecare and Support Services will complement and support such strategies to be implemented.

### **1.1. How the Draft National Standards will be developed**

The draft national standards will be informed by the evidence review presented in this document, along with stakeholder consultation. All documents and publications identified were reviewed and assessed for inclusion in the evidence-base to inform the development of the draft standards.

The Draft National Standards for Homecare and Support Services will be set out according to the principles outlined in the Standards Development Framework, which was published in September 2021.<sup>(2)</sup> These principles are:

- A human rights-based approach
- safety and wellbeing
- responsiveness
- accountability.

The draft national standards will consist of three sections:

- **Principle** — Following each principle, there will be an explanatory section setting out how a service works in line with that theme.
- **Standard statements** — The standard statement will describe the high-level outcome required to keep people safe and support them to maximise their potential. The standard statements will be written from the point of view of the person receiving the service.

- **Features of a service likely to be meeting the standard** — The list of features provided under each standard statement is not exhaustive and the service may meet the requirements of the standards in other ways. These features will be written from the point of view of the person using homecare services.

The principles, and the standard statements and features that support them, are intended to work together and collectively they describe how homecare and support services should be delivered to achieve safe, high-quality person-centred care.

This document provides the results of an extensive programme of research conducted by HIQA to underpin the standards which consists of:

- A **review of the context in Ireland** — this includes a description of the current model and arrangements for homecare in Ireland, an overview of legislation and policy, and a review of outcome data. This review was informed by academic papers, authoritative national websites, annual reports and statistical reports from key organisations, alongside collaboration with experts in this area. This review describes the context in which the Draft National Standards for Homecare and Support Services are being developed.
- An **international review of homecare and support services** in Scotland, England, Northern Ireland, Wales, the Netherlands, Australia and New Zealand. These seven jurisdictions were chosen following feedback from the scoping consultation, findings from the evidence synthesis and input from key stakeholders. A further desktop review, involving web-based searches of relevant literature and websites, identified a number of key organisations and experts to contact and engage with. The international review includes a review of information from authoritative international websites, national reviews, annual reports and statistical reports from key organisations, academic papers and teleconferences with international experts in this area. This section of the document describes the international models and arrangements for homecare and support services, relevant legislation, policy and standards, and available outcome data. This section provides international context and lessons to inform the development of draft standards in Ireland. In addition, as part of its international review, HIQA engaged with key stakeholders in international jurisdictions.\*

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\* See Appendix for a list of the organisations that HIQA engaged with during the development of this evidence review.

- A **literature review** of relevant academic material relating to good practice in the development and delivery of homecare and support services drawn from search databases.

The Draft National Standards for Homecare and Support Services will also be informed by extensive stakeholder engagement. HIQA has convened an advisory group comprised of a diverse range of stakeholders, including representatives from support and advocacy groups, regulatory bodies, professional representative organisations, such as the Department of Health, Health Service Executive (HSE), advocacy groups, and professional bodies representing homecare and support service providers. The function of the group is to advise HIQA and to support consultation and information exchange.

HIQA also held a public scoping consultation in October 2021, which involved consulting with people who have experience of homecare and support services. The consultation gave people an opportunity to identify the key areas that the standards should address and to provide examples of good practice. HIQA received 181 responses to the public scoping consultation from a wide range of individuals and organisations with experience of homecare and support services.

HIQA has undertaken extensive consultation and focus groups with service providers, homecare and support staff, family carers, people using homecare and support services, advocacy groups, charities and professional bodies. In addition to this, HIQA will undertake a public consultation process for members of the public and all interested parties to submit their views on the draft standards.

Following approval by the Board of HIQA, the standards will be submitted to the Minister for Health for approval. The approved standards will be made publicly available on the HIQA website.

## **1.2. Structure of this report**

This document sets out the findings of the review undertaken to inform the development of the Draft National Standards for Homecare and Support Services as follows:

Section 2: Overview of homecare and support services in Ireland

Section 3: International Review

Section 4: Evidence Synthesis Methodology

Section 5: Evidence Synthesis Findings

Section 6: Summary, Conclusion and Next Steps

## **Overview of the Irish context**



## 2. Overview of the Irish context

### 2.1 Homecare and support services in Ireland

In Ireland, homecare services are publicly funded by the HSE. The primary goal in delivering homecare and support services to people in Ireland is to allow them to live at home for as long as possible, if they wish to do so. There has been increased demand placed on the homecare and support sector in Ireland due to many factors. These factors include an ageing population, a move away from institutional care and a fragmented distribution of homecare and support services, including the outsourcing of publicly-funded homecare and support services, which has driven a competitive private or for-profit providers' market.

Ireland's growing and ageing population is higher than the average for EU countries, leading to greater demands across primary, acute and social care services and the need to move care towards community, home and prevention approaches. It is estimated that the number of people aged over 65 years in Ireland is increasing by approximately 20,000 each year.<sup>(21, 22)</sup> According to the 2016 Irish census, there were 637,567 people aged 65 years and over living in Ireland. Of this number, 224,388 people reported having a disability. In addition, population growth estimates indicate a 38% increase in people aged over 65 years and a 68% increase in people aged over 85 years by 2031.<sup>(23)</sup> The number of people living with dementia in Ireland is estimated to increase from approximately 55,000 people in 2016 to over 150,000 people in 2046.<sup>(22)</sup>

The COVID-19 pandemic highlighted infection control issues associated with congregated settings, resulting in a focus on supporting people to remain in their own homes to provide safer protection against infectious outbreaks.<sup>(4, 24, 25)</sup> A review conducted by HIQA on the impact of COVID-19 on nursing homes in Ireland recommended a reform of Ireland's social model of care for older people. This included services such as homecare and support, assisted-living and day-care to address the move away from the traditional model of nursing home care.<sup>(26)</sup>

There is currently no statutory regulation of homecare and support services in Ireland, resulting in concerns relating to quality-assurance, accountability, training and skills. This has also led to variations in resource allocations and subsequently service provision across the country.<sup>(27)</sup> There has been long-standing requests for the introduction of legislation to support and safeguard people using homecare and support services in Ireland from successive governments, researchers and advocacy groups. In addition, the current homecare and support sector is largely reliant on informal carers providing care to people to live in their own homes.<sup>(3)</sup> It is estimated

that informal carers provide approximately 60-90% of the total required homecare in Ireland and this is making up for the lack of resources available in formal home support.<sup>(3, 24)</sup> The Irish government has committed to introducing a standardised homecare and support service for the population of Ireland, as is evident in current legislative proposals to introduce regulations and national standards to the sector. A strong theme across the literature is an aim to provide person-centred care that is safe and high-quality that will facilitate people to live as independently as possible.

This section of the review provides a summary of how homecare and support is currently delivered in Ireland. It sets out the governance structures, key organisations and government documents that relate to homecare and support services. This section is structured under the following headings:

- Model of homecare and support service delivery
- Relevant legislation
- Standards, guidance, policies, frameworks and strategies
- Findings from reviews
- Summary.

Homecare and support services were traditionally referred to as 'home help' and 'homecare packages' in Ireland, but in 2018, these services were combined by the HSE to become known as 'home support services.' In addition, the terms 'homecare' and 'home support' are used interchangeably throughout the literature. For the purpose of this review, these terms will be used according to their use in the published literature under discussion.

## **2.2 The Model of homecare and support service delivery**

This section describes the landscape of homecare and support across Ireland and is set out under the following sub-headings:

- Structure and governance
- Scope
- Eligibility and assessment of need
- Commissioning and funding models
- Workforce.

## 2.3 Structure and governance

Homecare and support services in Ireland are provided and managed by the HSE with the Department of Health having overall responsibility for the public health system in Ireland. The HSE is an organisation established under Irish legislation (Health Act 2004) with statutory responsibility to manage and deliver health and personal social services to the Irish population.<sup>(28)</sup> The home support services funded by the HSE are either provided by staff directly employed by the HSE or by voluntary (not-for-profit) or for-profit (private) providers who are funded by the HSE to provide services through a tendering process. The overall responsibility for the governance of home support services rests with the Social Care Division in the HSE. The Economic and Social Research Institute (ESRI) reported that approximately 8.2 million hours of home support was provided by HSE staff members in 2019, equating to 33% of the total home support in 2019.<sup>(4)</sup> In addition, approximately 2.1 million hours (9%) was provided by the voluntary sector and 14.4 million hours (58%) was provided by private providers.<sup>(4)</sup>

Individuals may purchase home support services directly from private providers operating independently in the open market. The HSE has no oversight of these privately funded services. It was estimated that 11,600 people aged 65 years and over purchased home support directly from private providers in 2019.<sup>(4)</sup>

There is no national policy framework or related legislation governing homecare and support in Ireland and hence there is no statutory entitlement to homecare and support. Subsequently, the HSE is "empowered, but not obliged, to provide or fund community care services such as home care."<sup>(27)</sup> According to the 2018 review *Spotlight Home Care for Older People – Seven Policy Challenges*, approximately 50,000 people aged over 65 years (equates to approximately 8%) were in receipt of publicly-funded homecare in Ireland in 2017.<sup>(27)</sup> However, the lack of statutory backing has resulted in areas of inconsistency, for example regional variation and lack of clarity pertaining to eligibility criteria and allocation of resources. Homecare services are allocated based on need and availability of resources rather than ability to pay and thus, provision of homecare is subject to resource constraints and hence waiting lists are evident.<sup>(27)</sup> This review reported that approximately 4,600 people were on waiting lists for homecare, including new applicants and those waiting for additional hours.<sup>(27)</sup> A report from the ESRI indicated that this figure had increased to 5,436 in 2019.<sup>(4)</sup>

Publicly-funded homecare and support is organised through nine HSE Community Health Organisations (CHOs). Each CHO represents a geographical region in Ireland and is led by a Chief Officer with full responsibility and accountability for the delivery

of all community healthcare services in their area.<sup>(29)</sup> The CHOs feed into local health centres and primary care centres providing health and social care services in the community. Primary care centres may have a primary care team (PCT) which is a multidisciplinary group of health and social care professionals such as general practitioners (GPs), nurses, physiotherapists and occupational therapists. The GPs are independently contracted members of the PCT. The team work together to deliver a holistic, integrated and coordinated approach to health and social care needs in the community and can include home support services. The PCT can consist of home support coordinators, home helps and also community representatives. Community representatives can have multiple roles, ranging from involvement in participatory research to identifying local community health needs, to forming partnerships between the PCT and local authorities or agencies. In addition, PCTs can have a network of supports from other services: for example, psychology, audiology, podiatry, and dietetics.<sup>(28)</sup> However, there is variation in regional practices in Ireland, as the population served by a PCT is determined by geographical boundaries and or the practice population of participating GPs. There are 32 HSE Home Support Offices based at health centres and or primary care centres nationally. A home support service manager is accountable to the senior manager in the CHO and is responsible for the day-to-day management of home support services resources. The home support service manager or coordinator provides financial and non-clinical governance including Human Resources (HR) management support to the homecare and support workers. In addition, they work closely with the health professionals.<sup>(29)</sup>

PCTs can also have an extended role and provide Primary Care Paediatric Network-level Services for children, and comprises professionals with skills in paediatric care. In addition, there are Children's Disability Network Teams that provide services to children with a disability, including health and personal social services within the CHO under a Lead Agency Model. The team operate using a bio-psychosocial method that incorporates biological, psychological and social factors to deliver a holistic approach to all aspects of a child's life, particularly in the context of the community. The HSE introduced a Lead Agency Model as a structure for the future service delivery of children's disability services in 2019. Each lead agency has the responsibility for the provision of services for children aged 0-18 years with complex disability needs who have been assigned to the Children's Disability Network Teams. Disability needs can range from intellectual disability, physical disability, sensory disability and autism. The lead agency may be a HSE funded non-statutory organisation or a HSE CHO. Clinical governance within this model rests with individual health professionals being responsible for the quality of their own clinical practice and managers having responsibility for members of staff and ensuring

adequate training and supervision, performance and accountability arrangements are in place.<sup>(30)</sup>

The HSE developed a document with clear roles and responsibilities on clinical governance and the public health nurse or health professionals relating to home help services in 2014.<sup>(28)</sup> Clinical governance is described as a framework where healthcare teams are accountable for the care they deliver relating to quality, safety and level of satisfaction experienced by the person using the service. This document refers to home help under personal care (assistance with activities of daily living (ADL)) and domestic care (domestic duties (Instrumental Activities of Daily Living - IADL)). It places a responsibility on a healthcare professional who is usually a Public Health Nurse (PHN) or Community Nurse to give direction to the home help worker and the professional must be satisfied that the home help worker can perform the duties assigned to them. The health professional who is generally the PHN has responsibility for the clinical care of the person using the home support service on behalf of the HSE and hence is responsible for the care plan in terms of clinical, medical, and physical needs.<sup>(28)</sup> Table 2.1 presents the governance framework for home help services and distinguishes the roles and responsibilities for the HSE health professional and the home help coordinator.

**Table 2.1: Home Help Service - Governance Framework (2014)**

<b>HSE health professional - usually PHN or Community Nurse</b>	<b>Home Help Coordinator (may be employed by HSE or other Service Provider)</b>
Assess client care needs and document same.	Line Manager for Home Help workers.
Identify ADL and IADL deficits requiring support and document in care plan.	Responsible for the allocation of home help service in direct consultation with the key health professionals.
Determine the care inputs required to support the client's assessed care needs.	Prepare schedule of Home Help services in consultation with health professional(s), setting out hours and days of attendance.
Prepare and sign-off care plan in consultation with relevant other health professionals and with Home Help Coordinator.	Liaise with health professional(s) to agree appropriate level of home help input, within limit of available resources and competence.
Delegate personal care tasks to individual Home Help worker and supervise same.	Provide HR Support to Home Help service including staff supervision, leave Arrangements and payroll.

Orientate, instruct, guide and supervise the HSE Home Help workers in personal care needs in relation to the care plan for the individual client.	Support integrated service delivery across HSE disciplines.
Monitor or review personal care inputs delegated to HSE employed Home Help workers and monitor indirect service provision.	Undertake environmental risk assessments in consultation with relevant health professionals.
Monitor ongoing care of clients, including clients receiving home help services from external voluntary and private providers, on behalf of HSE.	Manage resources available for Home Help service.
Undertake care need reviews of clients as appropriate but at least once every six months for home help clients and once every three months where services are provided as part of a Homecare Package.	Review delivery of non-personal care tasks and environmental risks at appropriate intervals.
Monitor and raise any concern where it is clear or apparent that home help being procured privately by people or their families without HSE support is inappropriate or of a poor standard.	Provide point of contact for home help clients with home help service.

**Source:** HSE (2014). Home help governance framework.<sup>(28)</sup>

Despite this governance framework in 2014, it was highlighted in a review commissioned by the HSE in 2016 on Home Help services (HH) and Homecare Packages (HCP), that there was a lack of clarity regarding governance structures and it listed nine different staff titles that can be responsible for the service or that providers and employees can report to.<sup>(31)</sup> They included a General Manager, Home Help Manager, Public Health Nurse, and Manager of Community Services for Older People. This review recommended a single clinical governance structure within each CHO, with overall clinical responsibility resting with the Public Health Nursing team in each CHO and at national level. In addition, this should extend to the voluntary and private providers, thus facilitating a named person who has oversight over the care provided.<sup>(31)</sup> The *Home Support Service for Older People: Tender 2018: Service Specifications* published in 2018 added a specification pertaining to governance and is included under 'Governance and Accountability', which places the responsibility on the service provider to ensure that a clinical governance structure is in place. This governance includes appointing a person with explicit roles and responsibilities and informing the HSE, the person using the service and the staff employed by the service provider who this person is.<sup>(29)</sup>

## 2.4 Scope

The Department of Health has highlighted a lack of a standardised definition of homecare internationally.<sup>(13)</sup> The aim of homecare and support in Ireland is to facilitate a person of any age with care needs "to continue to live independently in their own home and community for as long as possible."<sup>(13)</sup> Emphasis is placed on maximising a person's ability to live at home and reduce inappropriate admissions to acute care services, in addition to supporting people with high levels of dependency and complex needs to stay at home, instead of entering residential care settings. Situations where homecare and support can be provided include care needs associated with a chronic condition or disability, or following a stay in hospital,<sup>(32)</sup> with older people representing a large proportion of people using homecare services. In some cases, exceptions are made where people who are under 65 years are placed under Older Persons Services for homecare and support. Examples of such cases include early-onset dementia, disabilities, and palliative care needs if assessed needs can be best met by the Older Persons Services. The HSE traditionally delivered Home Help services and a Homecare Package (HCP) scheme as separate services with separate funding arrangements but both were amalgamated in 2018 and are now referred to as Home Support Services. This amalgamation aimed to improve the "availability, accessibility and experience of these services for older people and their families."<sup>(29)</sup> The homecare and support services provided by the HSE are described herein under the following headings:

- Home Support Services
- Intensive Homecare Packages
- Paediatric Homecare Packages (PHCPs).

Home Support Services provides:

- Personal care (washing, dressing, oral hygiene, help at mealtimes), and essential domestic duties related only to the individual client (lighting a fire or bringing in fuel, essential cleaning of the person's personal living space, shopping). The domestic duties are also referred to as Instrumental Activities of Daily Living (IADLs).<sup>(29)</sup> An estimated 24.7 million home support hours were received across public and private home support in 2019.<sup>(4)</sup>

Intensive Homecare Packages provides:

- Support to people who require a very high level of assistance to be discharged from hospital or to avoid admission. It is a limited service that

includes high support needs over and above those provided as part of standard home support care. There are dementia-specific Intensive Homecare Packages supporting people living with dementia who have complex needs.<sup>(15)</sup>

Paediatric Homecare Packages provides:

- Support to children aged less than 18 years with complex needs, when these needs cannot be met by existing primary care services and children's disability services. This can include children with complex health conditions or palliative care needs and generally comprises of nursing staff and or care assistants. A range of paediatric conditions that are managed at home and require high care needs include epilepsy, tracheostomies, global developmental delay and cerebral palsy.<sup>(28)</sup> The HSE National Service Plan 2021 reported that there will be 616 PHCPs delivered during 2021, which indicates an increase of 100 packages since 2020.<sup>(28)</sup> PHCPs are provided by the HSE directly or commissioned by the HSE to voluntary or private providers through a tendering process. Ireland has a number of voluntary organisations providing homecare and support to children with life-limiting conditions and their families, such as the Brothers of Charity, LauraLynn Children's Hospice and the Jack & Jill Foundation. A review published by the ESRI in 2021 on the demand for homecare and support in Ireland highlighted limitations in available data on homecare and support services for children.<sup>(4)</sup>

A person requiring medium to high or very high levels of support are usually people with complex care needs who need the coordination and integration of different services and healthcare professionals across health and social care. Complex needs can include behavioural issues, emotional problems, mental health illnesses and medical treatments that place the person a higher risk than other people requiring home support.<sup>(29)</sup>

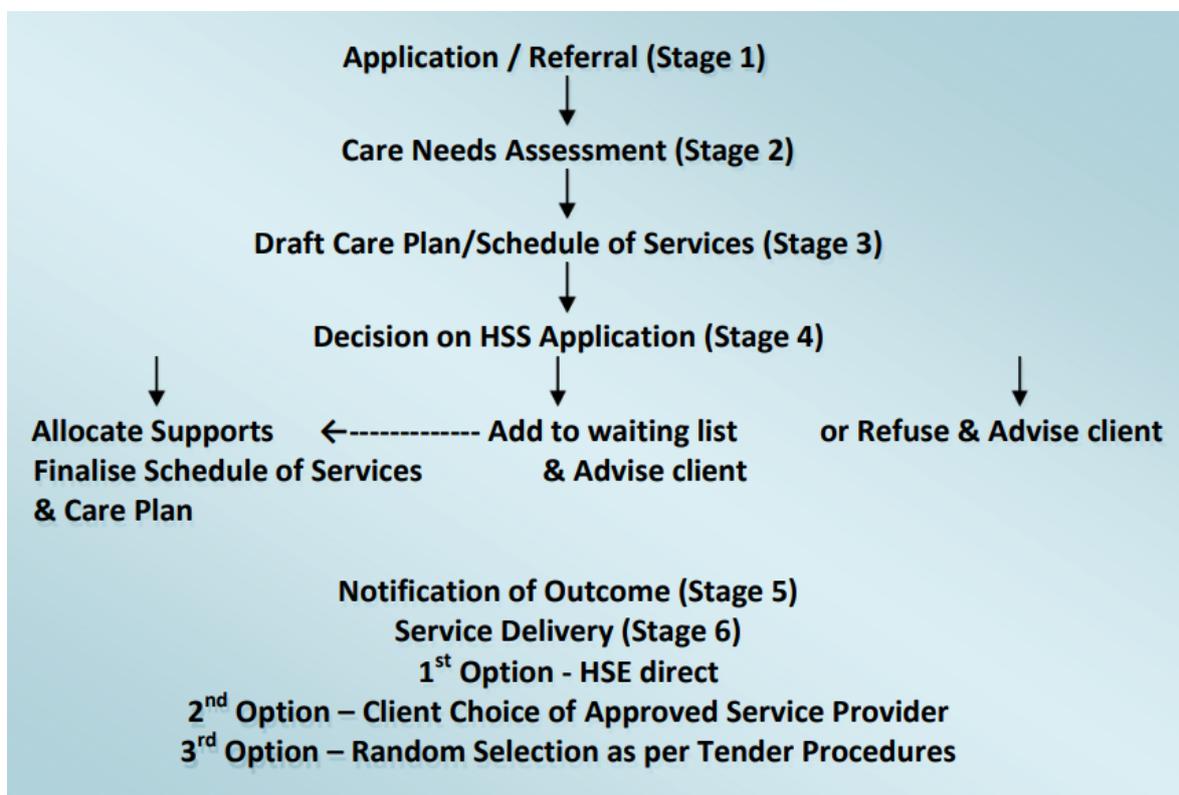
## **2.5 Eligibility and assessment of need**

An assessment of need is conducted to explore the appropriate supports and needs of the person. It is advocated by the HSE to involve family and or relevant carers in this process and emphasis is placed on a multi-disciplinary approach to assessment.<sup>(29)</sup> Access to home support is based on assessed need and is not means-tested. It begins with a person making an application to the HSE using a specific application form. A family representative can also complete the application on behalf of the person, providing that person has given consent. Once the application is processed, the HSE arrange for a member of staff, typically a public health nurse (or community nurse) to carry out assessments of the individuals' need

for home support services. A care needs assessment aims to identify the level of care and support needs and dependencies for a person in order to determine the appropriate assistance required for that person. In cases where resources have been fully allocated at local level and a waiting list exists, a prioritisation process is used to allocate services and or supports. An applicant's details are placed on the waiting list for home support when the support has been approved and all parties are fully committed to receive or deliver the service. The prioritisation process uses a ranking system based on risk assessment. A national risk assessment tool that measures likelihood and impact of a specific risk factor and those at higher risk will be prioritised for supports ahead of those who are deemed to have lower risks. In general cases, applicants are offered home support according to chronological date on the waiting list.<sup>(29)</sup>

If a number of professionals are involved or needed in the assessment process, one member of the multidisciplinary team acts as a key worker. The key worker coordinates completion of the care needs assessment and develops the home support plan. This plan identifies the exact service and assistance being recommended and will then be considered by the Home Support Manager in deciding the outcome of the application. The assignment of the home support worker is undertaken by the Home Support Manager and the health professional who has conducted the needs assessment and care planning. The assessment of need can also be conducted in a hospital setting to facilitate discharge home, in which case the level of need will be temporary, until a review of the person's home is conducted. Figure 2.1 displays the HSE Home Support Service Operational Processes and Procedures regarding application, assessment of need, draft support plan and approval process.

**Figure 2.1: HSE Home Support Service Operational Processes & Procedures**



**Source:** HSE (2015). Home Support Service Operational Processes & Procedures<sup>(33)</sup>

When a person is receiving home support services, the level of support will be reviewed by the relevant HSE staff, such as a public health nurse once every six months at a minimum and people receiving high levels of supports are reviewed at a minimum once every three months.<sup>(29)</sup> The reviews may result in an increase, decrease, continuation or discontinuation of the level of support, or referral to another service. Again, the provision of an additional service is dependent on available resources. This monitoring and review is undertaken regardless of the service provider being a HSE, voluntary or private provider.

The HSE introduced the Single Assessment Tool (SAT) in 2016. The SAT is a standardised information technology (IT) based tool that uses the interRAI or International Resident Assessment Instrument assessment system. It is an evidence-based assessment developed collaboratively by clinicians and researchers internationally. It is described as being user-friendly, reliable, and person-centred.<sup>(34)</sup> The SAT is similar to the interRAI homecare assessments and provides a comprehensive approach to assessing the health and social care needs of people who may be in need of supports, care planning and then service coordination.<sup>(34)</sup> Its many benefits include a reduction in fragmentation across services, value for money,

fairness and equity among people using home support services. In addition, the SAT is IT-based and thus reduces duplication in assessments, facilitates the exchange of information and ease of access to this information.<sup>(29, 34)</sup>

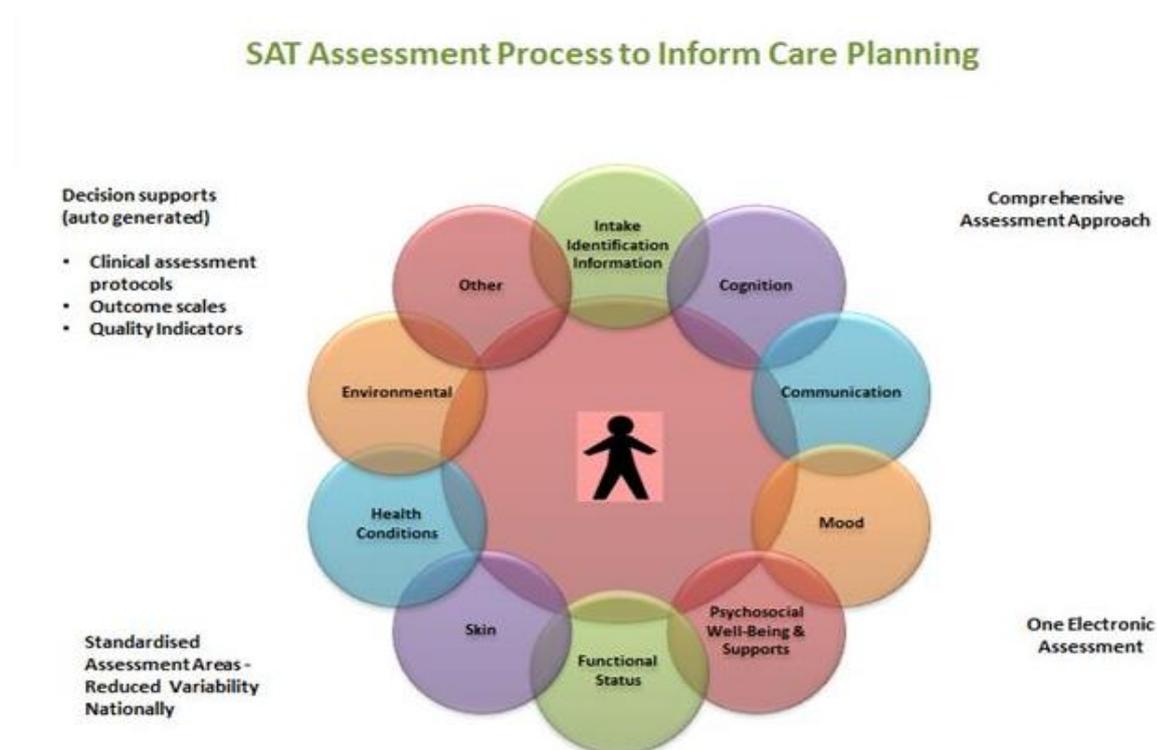
The SAT is used for older people or persons with disabilities who are seeking or receiving formal healthcare and supportive services, for example home support services. The tool provides a holistic approach to a person's condition, informing an individualised care plan. There are 20 different sections in the SAT that cover areas including cognition, communication, mood, psychosocial wellbeing and supports, functional status, skin, health condition, and environmental factors. These areas are displayed in Figure 2.2 and they assess the following:

- Ability to carry out the activities of daily living, for example personal hygiene, mobility, continence management, meal preparation and essential environmental care
- The medical, health and personal social services being provided to or available, both at the time of carrying out the assessment and in general from family and community supports
- Person's wishes and preferences.<sup>(34)</sup>

All sections in the SAT must be completed so data can be aggregated and coded to generate assessment outputs. These outputs are facilitators to decision-making, onward referrals and standards of care based on best evidence. In addition, the outputs will produce indices of risk, frailty, and prioritisation and thus, highlighting opportunities for improvement for the person and health outcomes. This can be reflected in the person's support plan.<sup>(34)</sup>

It is noteworthy that figures from the HSE National Service Plan 2019 report that the expected number of older people seeking community health services who had been assessed using the SAT was 300 during the last three months of 2019.<sup>(30)</sup> This questions its widespread use nationally when factoring in other figures such as 53,182 people in receipt of home support (excluding provision from Intensive Homecare Packages) in 2019. In addition, the HSE National Service Plan 2021 has indicated support for the full rollout of the SAT during 2021 and in doing so is supporting the appointment of 128 interRAI assessors.<sup>(34)</sup>

The HSE uses the Paediatric Community Assessment Tool (P-CAT) to assess the needs of a child with complex healthcare needs. This tool is based on a nursing assessment of need for firstly determining eligibility for the paediatric homecare package and then to plan and deliver the home nursing care and support.<sup>(28)</sup>

**Figure 2.2: Assessment process to inform care planning using the SAT**

**Source:** HSE (2021). Assessment process to inform care planning using the SAT<sup>(34)</sup>

## 2.6 Commissioning and funding models

The HSE delivers and funds home support services in Ireland. Adult home-support services are funded by the State through the budgets allocated annually to the HSE's Older Persons' Services and the HSE's Disability Services. Paediatric Homecare Packages are funded by a centralised and standardised process nationally. Publicly-funded home support is available free of charge for the population of Ireland, is not means tested and no contributions are required by the person using the home support service. However, funding is determined by a supply-led scheme and is dependent on available resources. A consultation report by the Department of Health, seeking to improve home support services in Ireland, estimated at the time of writing (2018) that approximately €408 million of the HSE's Older Persons' Services budget would provide over 17 million home support hours to approximately 50,000 people. In addition, the Disability Services budget would support approximately four million personal assistant and home support hours to people with disabilities.<sup>(13)</sup>

Home support services provided by the HSE are referred to as Formal Care (Public) and are delivered as follows:

- Direct Home Support – provided directly by the HSE
- Indirect Home Support – not-for-profit and for-profit providers, where service arrangements are in place following tender arrangements
- A combination of the above
- Consumer Directed Home Support (CDHS) – a programme where the person using the service is given control over who provides the services and how and when these services are delivered. It gives empowerment and autonomy to the person, allowing them to make informed choices about the types of services they access and the delivery of such services. The approval for CDHS is dependent on the person’s ability to control their service delivery, level of need and if they wish to use CDHS. Features of CDHS include:
  - a strong focus on person-centredness, with active involvement of the person or the person’s representative
  - the person may be given access to or control over a funding allocation
  - individualised service planning approach
  - the person can choose the services they receive and the mechanism for delivery, subject to key supports as identified through the needs assessment.

In addition, a person can purchase private homecare and support services and this is referred to as formal care (private) and the person may purchase private homecare and support as a supplement to publicly-funded home support hours provided by the HSE. Tax relief may be available for the purchase of private care in certain circumstances which may encourage those with the means to do so to pay for services.<sup>(13)</sup> The ESRI reported that approximately 25% (6.1 million hours) of all home support received in Ireland in 2019 was privately purchased.<sup>(4)</sup>

Homecare and support may also be provided by a family member or friends and is referred to as informal care. It has been highlighted that 60% of care given to people that enables them to live at home in Ireland is provided by informal carers.<sup>(3)</sup> The Irish census in 2016 reported that 195,263 people identified themselves as carers. Of these, 60.5% were female, and 52.7 % were between the ages of 40 and 59 years. The age group with the biggest increase in people identifying themselves as carers was the 85 years and over age group.<sup>(23)</sup> While this is mostly unpaid work, informal carers can apply for a carer’s benefit or allowance. In addition, there is a respite care grant that is an annual payment for full-time carers and allows the carer to use the grant in any way they wish. A housing adaptation grant is available from

local authorities if changes are needed in the home in order to make it more suitable for a person, depending on their circumstances.

The HSE manages the commissioning of home support services on a national scale. It operates in line with the limits and targets as set out in the HSE National Service Plan (NSP). The NSP agrees a set number of home support hours to be provided in any one year, within a definitive resource allocation. It is a fixed budget allocation and thus is a supply-led scheme. The CHOs are given the responsibility for the distribution of the funding on a local scale and is set out in their operational plans on an annual basis. There are separate funding arrangements for home support services, intensive homecare packages services and paediatric homecare packages.<sup>(29)</sup> The budget and allocations of resources are determined by the level of service delivery, targets and expected activity levels, for example, waiting lists or review of hours per clients.<sup>(27)</sup>

## 2.7 Workforce

Home support in Ireland is provided by staff employed by the HSE, voluntary and for-profit organisations. Home support workers in Ireland are not required to register with a professional health and social care registration body. It is also reported that the sector is challenged by staff recruitment and retention.<sup>(4)</sup>

A report published by the ESRI found that there were 5,703 home carers employed by the HSE to provide care to older people in the community in December 2019.<sup>(35)</sup> The majority of these HSE-employed home support workers were healthcare support assistants (previously referred to as home helps), with a small number being other types of carers such as healthcare assistants (HCAs). The report also highlighted that this sector is heavily dependent on the female workforce.<sup>(4)</sup> A homecare support worker is defined by the HSE as follows:

A homecare support worker is a person who works for the service provider which provides homecare services to people who live at home.<sup>(29)</sup>

The HSE published service specifications in 2018 that set out standards and specifications for home support service providers to comply with if under contract with the HSE.<sup>(29)</sup> The standards and specifications include a theme on Workforce adapted from HIQA's 2012 *National Standards for Safer Better Healthcare* <sup>(24)</sup> They begin with clear steps to recruiting home support workers, followed by training and development requirements. Emphasis is placed on induction and mandatory training and shadowing arrangements for new staff members. The recommended level of qualification attainment for working on HSE contracts specific to home support is a

Quality and Qualifications Ireland (QQI) major award at level five or higher in one of the courses listed in Table 2.2.<sup>(29)</sup>

**Table 2.2: The HSE recommended level of qualification for working on HSE contracts for home support**

Level	Title	Type
5	Health Service Skills	Major
5	Community Care	Major
5	Healthcare Support	Major
5	Nursing Studies	Major

**Source:** HSE (2018). Home Support Service for Older People Tender 2018 Service Specification<sup>(29)</sup>

In addition, a National Carers Competency Assessment exists and must be completed annually. This assessment determines if a home support worker is competent to undertake a given task as set out under the HSE contract for the service. If a staff member is deemed 'not skilled' in an area of care, then they will not be assigned to the individual or client. According to the HSE document (2014) on roles and responsibilities for the formally known home help service, it is generally the PHN or the community nurse who ensures that HSE employed home help worker's personal care competencies are reviewed and assessed.<sup>(28)</sup> These competencies should be consistent with the changing needs of the person receiving home support. The PHN or community nurse completes the competency assessment and certifies competencies as part of local or national training and in conjunction with requirements from certified training programmes as those described above.<sup>(28)</sup> The competency assessment addresses the following skills:

- Client Safety
- Communications
- Effective Team Member
- Personal Hygiene
- Promoting Continence
- Nutrition
- Social, Emotional & Cultural Care
- General Professional Ethos
- Pressure Area Care.

The ESRI identified a lack of information available on how many carers are employed in voluntary and private organisations and the skills of these carers. Therefore, little is known about the total number of carers employed in Ireland.<sup>(35)</sup> In addition, the

ESRI suggested the introduction of a carer register or regular large-scale carer surveys as an approach to collecting comprehensive data that would assist policymakers, employers, carers, and home support recipients.<sup>(4)</sup>

Paediatric homecare packages generally require the service of nurses who are skilled in paediatric care. Nurses who work in health and social care services in Ireland are required to register on the Register of Nurses and Midwives, which is kept by the Nursing and Midwifery Board of Ireland (NMBI). NMBI is an independent statutory organisation responsible for regulating the nursing and midwifery professions in Ireland. NMBI places a duty on registered nurses to maintain their own continuous professional competencies. There have been recommendations from the HSE (2016) for a review of nurse education and training at undergraduate level, so that it corresponds with the changing needs of health service delivery.<sup>(22)</sup> An example of changing needs include the new focus on caring for children in community settings, as seen in the National Model of Care for Paediatrics and Neonatology.

## **2.8 Relevant Legislation**

There is currently no legislation or statutory regulations underpinning homecare and support services in Ireland. However, homecare and support services are provided through the HSE and the HSE was established under the Health Act 2004. The Disability Act 2005 relates to the provision of care for people with a disability. The Children First Act 2015 places a duty on services providing care to children to protect the welfare of children. The Assisted Decision Making (Capacity) Act 2015 applies to homecare and support services and is about supporting decision-making and maximising a person's capacity to make decisions. There is currently a Health (Amendment) (Professional Homecare) Bill 2020 under consideration with government. This section describes the four pieces of legislation and the proposed Homecare Bill as they relate to homecare and support.

### **2.8.1 Health Act 2004**

The Health Act 2004 sets out the functions of the HSE in delivering health and personal social services in Ireland. Functions include: the integration, coordination and commissioning of health and social care services; education and training of healthcare professionals; responses to government policies and objectives; and the conduct of research. In addition, the legislation details the HSE's accountability structures, complaints procedures and the dissolution of certain health boards and authorities that had previously administered health services.<sup>(25)</sup>

## 2.8.2 Disability Act 2005

The Disability Act 2005 places a legal duty on public service providers such as the HSE to support access to services for people with disabilities. The aim is to provide disability-specific services and promote the participation of people with disabilities in society. The Act sets out that people with disabilities are entitled to an assessment of educational and health needs, access to independent complaints and appeals procedures and access to information. The definition of the term 'Disability' used in the legislation is:

Disability in relation to a person means a substantial restriction in the capacity of the person to carry on a profession, business or occupation in the State or to participate in social or cultural life in the State by reason of an enduring physical, sensory, mental health or intellectual impairment.<sup>(36)</sup>

### 2.8.2.1 Disabled Persons Organisations

Disabled Persons Organisations (DPOs) are national representative organisations for disabled people and were established in 2019 in accordance with the Convention on the Rights of Persons with Disabilities (CRPD). The overarching aim is to ensure disabled people have full participation, understanding and promotion of their interests. There is an obligation on the Irish State to actively involve and prioritise DPOs as representatives for disabled people relating to public consultations, decision-making, policy and legislation developments.

## 2.8.3 Children First Act 2015

The Children First Act 2015 was enacted in 2015 and fully commenced in 2017. The Act works in conjunction with *Children First: National Guidance for the Protection and Welfare of Children (2017)* which will be discussed under section 4.4. It places a statutory obligation on professionals working with children and organisations providing services to children to comply with a number of child protection and safeguarding measures. The overarching intention of the Children First Act is raising awareness of child abuse and neglect and the reporting of any child abuse. Duties placed on organisations include the following requirements:

- To keep children safe and to produce a Child Safeguarding Statement
- To appoint mandated persons to report child protection concerns over a specified threshold to the Irish Child and Family Agency (Tusla). The mandated person must assist Tusla as much as reasonably required in the assessment of a child protection risk. The Act includes a list of 18 classes of persons who are defined as mandated persons. They are people who have

contact with children and or families who, by virtue of their qualifications, training and experience, are in a key position to help protect children from harm. Mandated persons include key professionals working with children in the education, health, justice, youth and childcare sectors.

- To establish the Children First Inter-Departmental Implementation Group. This group includes representatives from all government departments, Tusla, HSE and An Garda Síochána (Ireland's National Police Service). The functions of this group is to promote, review and report on compliance with the provision of the Act and each Minister of the Government is responsible for preparing a sectoral implementation plan.<sup>(37)</sup>

#### **2.8.4 The Assisted Decision-Making (Capacity) Act 2015**

The Assisted Decision-Making (Capacity) Act 2015 was enacted into law in 2015 and applies to all health and social care services in Ireland. This legislation sets out a legal framework of supports taking a rights-based approach to decision making. The framework is underpinned by the presumption of capacity to make decisions about one's own life, regardless of age, diagnosis or disability. The Act places an obligation on health and social care services to support a person to make their decisions regarding needs and preferences. In addition, situations where a person's capacity is in question, that person's right to make their own decisions should be supported and maximised.<sup>(37)</sup>

Section three of the Act takes a functional approach to capacity and sets out that a person's capacity should be assessed on his or her ability to understand, at the time that a decision is being made. Subsequently, decision-making capacity can fluctuate according to time, issue and context. In addition, there are guiding principles underpinned by Human Rights principles that assist with assisted decision making.<sup>(37)</sup>

If an event occurs where a person is unable to make a decision, there are levels of support arrangements set out in the Act. Emphasis is placed on access to support and assistance with decision-making, subsequently maximising participation, autonomy and equality in a person's own life decisions. People can be appointed at different levels to support people with decision-making, such as those relating to personal welfare, property or affairs are referred to as: decision-making assistant; co-decision-maker; and decision-making representatives. In addition, the Act sets out procedures pertaining to advance healthcare directives and enduring powers of attorney for individuals who has difficulty or lack capacity to make a decision.<sup>(37)</sup>

The Decision Support Service was established under the Assisted Decision-Making (Capacity) Act 2015. The Decision Support Service is expected to be fully in effect in

2022, with an overarching aim of ensuring Ireland is compliant with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). The service will aim to protect and uphold people's rights with decision-making. It will have a range of roles and functions including regulation, supervision, and maintenance of a panel of experts acting as decision-making representatives, investigating complaints and promoting information about the legislation to enhance awareness.

### **2.8.5 Health (Amendment) (Professional Homecare) Bill 2020 and Health (Amendment) (Licensing of Professional Home Support Providers) Bill**

The Law Reform Commission conducted a review of the home support sector in Ireland in 2011.<sup>(38)</sup> They recommended that legislation be enacted governing homecare services. The Law Reform Commission review included the draft health (professional homecare) Bill 2011, which has since been amended a number of times and has been renamed the Health (Amendment) (Professional Homecare) Bill 2020 in the past and more recently the Health (Amendment) (Licensing of Professional Home Support Providers) Bill.

The proposed Bill seeks to amend the Health Act 2007 so that it provides for the regulation of professional homecare. The Health Act 2007 was enacted to establish HIQA in Ireland. The Act sets out the roles and functions of HIQA, including setting national standards, regulating, monitoring and inspecting health and social care services.<sup>(39)</sup>

At the time of writing, the current Draft Heads of Bill have not yet been finalised. However the original Bill outlined in the Law Reform commission report in 2011 proposed a number of amendments to the Health Act 2007 including the definition of Designated Centre (Health Act 2007), standards for professional homecare and general duties concerning professional homecare services.<sup>(39)</sup>

In an Oireachtas debate on 24 September 2020 it was agreed that the Health (Amendment) (Professional Homecare) Bill 2020 would be adjourned for 12 months, to allow the Minister for Health to further consider some of the issues with the Bill and it was reported that the Minister for Health was "already in the process of developing a comprehensive regulatory framework to regulate home support services".<sup>(40)</sup> It was proposed that the appropriate approach to adopt to the regulation of home support providers would be to develop a bespoke licensing system.

The Minister for State reported that HIQA supports this approach, explaining that in its March 2017 paper, "Exploring the regulation of health and social care services -

Older People's services", HIQA recommended a service provider-based approach and a model of registration based around the service provider.<sup>(41)</sup>

The approach proposed by the Minister of State would encompass three elements:

- Primary legislation to regulate home support services through the licensing of public and private providers
- The development of minimum standards by the Department of Health that would form the criteria against which the regulator would determine whether a home support service is of the requisite standard for the provider to be licensed to operate
- The development of national standards for home support services by HIQA.<sup>(41)</sup>

On 13 January 2021 the Department of the Taoiseach published *The Legislative Programme Spring Session 2021*. This programme included reference to a bill called the Health (Amendment) (Licensing of Professional Home Support Providers) Bill. The purpose of this Bill was described as "to regulate home-support services through the licensing of both public and private providers."<sup>(39)</sup> In April 2021, the Irish Government approved the drafting of a General Scheme and the establishment of a licensing framework for publicly funded, for-profit and not-for-profit home support providers. This will form one part of a regulatory framework for home support services that is currently being developed by the Department of Health.<sup>(42)</sup>

## **2.9 Standards, Guidelines, Policies, Frameworks and Strategies**

This section describes standards, guidelines, national policies, frameworks and strategies that have been developed to promote and support the provision of homecare and support services in Ireland. There is a strong focus on the need for improvements in homecare and support delivery, in order to move away from residential care where appropriate and this will be discussed under Standards, section 2.9.1. In addition, national guidelines and policies will be summarised under section 2.9.2 and 2.9.3 and then national health frameworks and strategies under section 2.9.4 and 2.9.5 respectively.

### **2.9.1 Standards**

There are currently no nationally endorsed standards for homecare and support services in Ireland. However, some specific standards such as the *National Standards for Adult Safeguarding* and *National Standards for Infection Prevention and Control in Community Services* apply to homecare and support services and will be discussed under section 2.9.1.1 and 2.9.1.2. In addition, standards that can be

applied to homecare and support have been published by a representative organisation for private homecare providers, Home and Community Care Ireland (HCCI) and will be summarised under section 2.9.1.3. The HSE developed service specifications as part of a tendering process for home support services. These specifications are set out according to the *National Standards for Safer, Better Healthcare (2012)* and hence will be discussed in this section under 2.9.1.4.

### **2.9.1.1 National Standards for Adult Safeguarding (2019)**

The *National Standards for Adult Safeguarding (2019)* were jointly developed by HIQA and the Mental Health Commission. The standards are underpinned by six key principles: empowerment, a rights-based approach, proportionality, prevention, partnership and accountability. The aim of the standards is to improve the experience of all people accessing health and social care services, reduce their risk of harm, and promote their rights, health and wellbeing. They apply to all residential services for older people and people with disabilities, all publicly-funded health and social care services and all mental health services and hence includes homecare and support services. Safeguarding is fundamental to high-quality health and social care. The national standards provide a framework for best practice in safeguarding adults in health and social care services in Ireland.<sup>(43)</sup>

### **2.9.1.2 National Standards for infection prevention and control in community services (2018)**

The *National Standards for infection prevention and control in community services (2018)* were developed by HIQA and apply to all community services, including homecare and support services. The standards are made up of 20 outcome statements and cover areas such as communicating well with people who use community health or social care services, involving people in making decisions about their care, providing care in a clean and safe environment and prescribing antimicrobial medication in a safe manner. The standards make the distinction that certain features associated with a standard do not apply to a person's own home, for example, features that refer to facilities. Facilities are owned or operated by a service provider and thus, do not include a person's own home where homecare and support services and or public health nursing is provided.<sup>(44)</sup>

### **2.9.1.3 Home and Community Care Ireland - National Standards for Provision of Homecare Support Services**

The *National Standards for Provision of Homecare Support Services* were developed by Home and Community Care Ireland (HCCI) and are described as being based on the *HSE National Quality Guidelines for Homecare Support Services* and the *HSE*

*Agreement with Homecare Providers for the Provision of Homecare Services in LHO Dublin North West for Older Persons Service/for Disabilities Services.*<sup>(25)</sup> HCCI is a national membership organisation for companies that provide a managed homecare service in Ireland. Organisations have to meet the criteria as set out in HCCI National Standards in order to become a member. The HCCI reports that members undergo an independent audit to ensure they meet the standards. The standards are statements describing a process of care and include criteria or lists that demonstrate compliance with the standard. They cover the following areas:

1. Referral, assessment and care planning
2. Staff recruitment and selection
3. Staff training and development
4. Protection of the person from abuse or exploitation
5. Quality assurance
6. Premises, management and planning systems
7. Handling complaints
8. Miscellaneous employment related issues.<sup>(25)</sup>

#### **2.9.1.4 Home Support Service for Older People: Tender 2018: Service Specifications**

The HSE developed a set of service specifications that home support providers must demonstrate compliance with, as part of the tender process for home support services for older people. There are 23 specifications in total and they are arranged under the eight themes associated with the *National Standards for Safer Better Healthcare (2012)*.<sup>(24)</sup> These national standards were developed by HIQA, the national body with responsibility for setting health and social care standards in Ireland. The specifications and themes are listed in Table 2.3. The specifications are set out using outcome statements describing compliance with the specification.<sup>(29)</sup>

The specifications document includes a list of policies and procedures (22 in total) that all home support service providers should have in place. In addition, quality assurance is based on self-audit, with a self-declaration assessment for completion on a quarterly basis. The HSE can conduct an audit of the self-declaration assessments.<sup>(29)</sup> The self-audit is based on four key performance indicators (KPIs) and are described as follows:

##### **1. Training and or Qualifications**

- Refers to the qualification standards set out for home support workers and providers must self-declare the percentage of their staff that have

successfully completed training modules within timescales set out in the service specifications.

**2. Home Support Plans** – Service delivery in accordance with plan – “No Show”

- Refers to the delivery of care as set out in the clients home support plan. The provider must declare the number of episodes that the home support worker did not show up for an episode of home support or showed up late.

**3. Home Support Plans** – Service delivery in accordance with plan – Timely acceptance of work and delivery to plan

- Refers to the time it takes the provider to accept or reject offers of work and the time from acceptance of work to the delivery of the required home support plan. There is an expectation on providers to respond promptly to the HSE’s offer of work and the timescale is determined by the HSE service manager. This is to avoid unnecessary delays in service provision.

**4. Quantum of service delivered**

- Refers to the provider’s capacity to deliver the work offered by the HSE. This is based on the provider’s acceptance, non-acceptance or non-responses of services offered by the HSE.<sup>(29)</sup>

Penalties for under-performance or non-compliance with the KPIs are agreed in the service contracts and escalated accordingly including:

- suspension from the agreement for a defined period of time
- removal of existing packages due to non-responsiveness to requests for services or failing to meet response times or failure to deliver the required services or duty of care concerns
- termination of the agreement.<sup>(29)</sup>

**Table 2.3: List of Specifications under themes from National Standards for Safer, Better Healthcare (2012)**

Theme 1: Person-Centred Care and Support	
Specification 1	Principles of Service Delivery
Specification 2	Information
Specification 3	Communication

Specification 4	Complaints
Specification 5	Consent
<b>Theme 2: Effective Care and Support</b>	
Specification 6	Care Needs Assessment
Specification 7	Home Support Plan
Specification 8	Policies and Procedures
Specification 9	Quality Control
<b>Theme 3: Safe Care and Support</b>	
Specification 10	Safeguarding and Protection of Service User
Specification 11	Security of the Home
Specification 12	Medicines Management
<b>Theme 4: Better Health and Wellbeing</b>	
Specifications 13	Better Health and Well Being
<b>Theme 5: Leadership, Governance and Management</b>	
Specification 14	Governance and Accountability
Specification 15	Financial Procedures
<b>Theme 6: Workforce</b>	
Specification 16	Recruitment
Specification 17	Training and Development
Specification 18	Supervision of Staff
Specification 19	Health and Safety
Specification 20	Non-Discrimination
<b>Theme 7: Use of Resources</b>	
Specifications 21	Resources

Theme 8: Use of Information	
Specifications 22	Records
Specification 23	Confidentiality

**Source:** HIQA (2012). National Standards for Safer, Better Healthcare.<sup>(24)</sup>

## 2.9.2 National guidelines

This section will summarise national guidelines developed by the HSE to enhance the implementation of the homecare and support process for service providers. National guidelines encompass standard operating procedures and guidance and are described under: Home Support Service for Older People Standard Operating Procedure (SOP) Tender (2018); National Guidelines & Procedures for the Standardised Implementation of the Home Support Service (Home Support Services (HSS) Guidelines) (2018); Children First: National Guidance for the Protection and Welfare of Children.

### 2.9.2.1 Home Support Service for Older People, Standard Operating Procedure (SOP) Tender (2018)

The Home Support Service for Older People, Standard Operating Procedure (SOP) Tender (2018) was developed following the amalgamation of the Home Help Service and Homecare Package Scheme. The aim was to streamline the home support service and enable easier access for people using services. The SOP is divided into three sections:

1. Operational procedures for the service, incorporating the Tender Service Agreements and the National Guidelines and Procedures for the Standardised Implementation of the Home Support Service.
2. Management and Monitoring of Service Arrangements (SAs).
3. Administration and data collection relating to analysing implementation of SAs.<sup>(29)</sup>

These three sections are detailed below:

#### Section 1: Operational Procedures

This section is written in conjunction with the National Guidelines and Procedures for the Standardised Implementation of the Home Support Service (HSS Guidelines) as discussed in section 4.2.2. It sets out the tender process when situations arise where

the HSE is not able to deliver home support services directly. This section is subdivided into smaller sections outlining procedures for different elements of the tender process and are listed as:

- i. Client Application and Determination
- ii. Procedures for allocation of all New Home Support Service (HSS) to 'Approved Providers'
- iii. Operation of Arrangements
- iv. Thirty Minute Calls
- v. Getting the HSS Started
- vi. Payments to Approved Providers
- vii. Withdrawal of Service
- viii. Change of Carer
- ix. Confirmation Service has been delivered to Client
- x. Client Monitoring & Review and Complaints
- xi. Use of HSE Logo by Approved Providers.<sup>(29)</sup>

The document outlines that it is expected that the HSE uses its own directly employed staff to provide home support services where possible. In cases where the HSE does not have sufficient capacity, then external providers should be used and they should be 'Approved Providers' on the approved list. All grant funding goes through the 2018 tender arrangements. An Approved Provider must deliver the full home support requirement offered by the HSE. They cannot choose to deliver a portion of a home support service. In addition, the HSE will follow the 2018 Tender Framework, whereby the HSE assesses and approves hours and service requirements based on an assessment of need. The person using the service will be provided with a list of Approved Providers and will select their preferred provider. It is recommended that a standard time and response time will be arranged for communications between the HSE and Approved Providers. There is guidance on how to manage 30 minute calls, in which the HSE has the right to allocate 30 minutes where appropriate. The home support provider manager must keep administration records.<sup>(29)</sup>

## **Section 2: Management and Monitoring of Service Arrangements**

The HSE National Governance Framework informs the management of service arrangements, including the monitoring of approved HSS providers. However, at the time of writing the SOP, the Tender 2018 Service Arrangements were in the process of being finalised and hence, there was a plan to issue "the final agreed documents and processes relating to the Service Arrangements for Home Support" separately. Four key performance indicators (KPIs) are used and service providers are expected to complete a self-declaration every three months and submit it to the Home

Support Service Manager or Head of Social Care. The HSE determines if performances reflect experiences such as complaints received, spot checks, and service user confirmation of service delivery. KPIs and related penalties for non-compliance are discussed under section 4.1.4. The HSE must monitor 'Approved Providers' approximately once a year including on-site audit. This incorporates service user reviews and regular meetings with each service provider. The CHOs are responsible for monitoring the 'Approved Providers.'<sup>(29)</sup>

### **Section 3: Data**

This section sets out the responsibilities of each CHO regarding data collection, monitoring and responding to tender arrangements, KPI data and monthly reporting of the Home Support Dataset. Specific data for inclusion in the Home Support Data Recording System includes details of people using services, home support tender rates, approved provider selection mechanism and reviews from people using services. Monitoring data includes KPIs, staffing details, and audit and review reports.<sup>(29)</sup>

Finally, the SOP provides appendices including guidance on travel costs, templates for data collection and KPIs, service user and or client "Information on Choosing a Home Support Approved Provider."<sup>(29)</sup>

#### **2.9.2.2 National Guidelines & Procedures for the Standardised Implementation of the Home Support Service (Home Support Services (HSS) Guidelines) (2018)**

The HSE published *National Guidelines and Procedures for the Standardised Implementation of the Home Support Service (HSS Guidelines)* in 2018. The aim of the guidelines is to provide guidance and procedures to home support service providers for older people including service operations and funding practices.<sup>(29)</sup> It is expected that adherence to these guidelines will facilitate a consistent approach to processing and assessing home support across the HSE and CHOs. The scope of the guidelines is personal care and essential domestic care for older people using home support services. It also places a focus on the assessed needs of people with dementia. The guidelines set out clear approaches to care including access to home support services, decision-making, care needs assessments, operational processes and procedures, Consumer Directed Home Support (CDHS), management of resources and waiting lists, monitoring and review and implementation of the guidelines.<sup>(29)</sup> In addition, guidance on standardised documentation, for example a Home Support Service information booklet and an application form are included.

### **2.9.2.3 Children First: National Guidance for the Protection and Welfare of Children**

The Children First Act 2015 and *Children First: National Guidance for the Protection and Welfare of Children (2017)* were developed and implemented conjointly and are referred to as Children First. The guidance is a national policy document to promote the safety and protection of children from abuse and neglect. It describes four main types of child abuse, and signs for its recognition, and then details steps to take to report a concern about a child. It sets out the statutory responsibilities for mandated persons and for services under the Children First Act 2015. The role of the Child and Family Agency (Tusla) as the organisation with responsibility for child welfare and protection in Ireland and An Garda Síochána (Ireland's National Police Service) are outlined in relation to dealing with concerns of abuse. Emphasis is placed on inter-agency collaborations in managing concerns about children's safety and welfare. The guidance is complemented by an e-learning programme called 'Introduction to Children First.' It is mandatory that all HSE staff (permanent, temporary, agency, locum or visiting) including students and volunteers, irrespective of role or grade and HSE-funded agencies complete this e-learning programme. Staff belonging to HSE contracted services such as home support services are strongly urged to complete this training.

### **2.9.3 National Policies**

This section describes a number of national policies that set out the safety and quality processes that should be embedded in homecare and support services. National policies have been developed and published by the Department of Health, HSE and the Health and Safety Authority (HSA). The following national policies are described in this section:

- Sharing the Vision: A Mental Health Policy for Everyone (2020)
- Personal Data Protection Policy (2019)
- National Consent Policy (2019)
- Safe Driving for Work Policy (2018)
- Policy on the Prevention and Management of Work-Related Aggression and Violence (2018)
- Occupational Safety and Health and Homecare (2017)
- Policy on Lone Working (2017)
- Protecting HSE Staff from Second-hand Smoke in Domestic Settings Policy (2014)
- Dignity at Work Policy for the Health Service, Anti Bullying, Harassment and Sexual Harassment Policy and Procedure (2009)

- Trust in Care, Policy for Health Service Employers on Upholding the Dignity and Welfare of Patient/Clients and the Procedure for Managing Allegations of Abuse against Staff Members (2005)
- HSE Your Service Your Say.

### **2.9.3.1 Sharing the Vision: A Mental Health Policy for Everyone, Department of Health (2020)**

*Sharing the Vision: A Mental Health Policy for Everyone* recognises the need for a united approach from all populations and governments in the delivery of mental health services. The policy is underpinned by an ecological model referred to as a 'stepped care approach' that ensures that the values from Sharing the Vision are preserved throughout the care process. A stepped care approach aims to promote that each person has access to a range of options of varying intensity to match their needs.<sup>(39)</sup> This means that care needs can be flexible by means of stepping up or stepping down in accordance with a person's recovery. Mental health services can include promotion, prevention, early intervention, recovery and participation. Capacity of such services needs to assess alternatives to acute in-patient care such as homecare teams, outreach teams and day hospitals. Day hospitals and home-based care teams provide continuous integrated care in partnership with other services. In addition, they provide intensive support to individuals with severe mental health difficulties or those with first incidence presentation who are in crisis. Typically, these supports include a range of therapeutic approaches, including medication management, cognitive and behavioural interventions and evidence-informed family interventions. The teams provide a rapid response and 24-hour service, with support provided in one's own environment and with the active involvement of the person using the services and their family, carers and supporters, and liaison with local health professionals such as GPs. Home-based crisis resolution teams could also play a role in supporting out-of-hours crisis cafés.<sup>(39)</sup>

### **2.9.3.2 Personal Data Protection Policy, HSE (2019)**

The *Personal Data Protection Policy* begins with the HSE's obligation to comply with data protection, privacy and security laws and regulations and subsequently to embed a culture of honesty, compassion, transparency and accountability. Data should be processed and controlled according to General Data Protection Regulation (GDPR) principles and relevant Irish legislation. The high-level principles described in this policy are:

- Principles of Lawfulness, Fairness and Transparency
- Principle of Purpose Limitation

- Principle of Data Minimisation
- Principle of Accuracy
- Principle of Data Storage Limitation
- Principles of Integrity and Confidentiality
- Principle of Accountability.<sup>(30)</sup>

The Office of the Data Protection Officer should be notified and involved in all issues relating to the protection of personal data and has responsibility to monitor compliance with GDPR and the overall control of how data is process within the HSE.<sup>(30)</sup>

### **2.9.3.3 National Consent Policy, HSE (2019)**

The *National Consent Policy* is a policy developed by the HSE to guide staff working in health and social care services on the application of consent in practice. The scope of the policy is for use with any person using services in hospitals, in the community and in residential care settings. Consent is defined as “giving permission or agreement for an intervention, receipt or use of a service, or participation in research following a process of communication in which the service user has received sufficient information to enable him/her to understand the nature, potential risks and benefits of the intervention or service.”<sup>(30)</sup> There are four sections to this policy. The first section sets out the general principles of consent including consent in Irish law, capacity with decision-making, voluntary consent, and refusal of consent. Section two describes consent in relation to children or minors, including the role of parents and legal guardians, age of consent and refusal of consent. Section three addresses the area of research and consent. Section four describes do not attempt resuscitation (DNAR) orders including the general principles of DNAR, balancing the benefits and risks of cardio-pulmonary resuscitation, DNAR decisions and children.<sup>(30)</sup>

### **2.9.3.4 Safe Driving for Work Policy, HSE (2018)**

The *Safe Driving for Work Policy* was developed in response to the HSE’s obligation under the Safety, Health and Welfare at Work Act 2005 to ensure work related road safety. The policy explicitly explains that driving for work refers to “any person who drives on a road as part of their own work.”<sup>(29)</sup> The policy indicates that local guidelines or Standard Operating Procedures should be in place to support the implementation of this policy. Roles and responsibilities to implement this policy lie with a range of staff members, from system level to management level to individual employee level. Primary roles include identifying, evaluating, managing, monitoring and auditing of the policy and risks associated with work related road safety. The

policy lists responsibilities in relation to driving a HSE vehicle such as approvals based on: driver's age; experience; training; fitness to work; monitoring and reviewing the driver performances following penalty points; right to see a person's driving license; adherence to the rules of the road and speed limits; notifying line manager of change in medical status. If drivers are driving their own vehicles, responsibilities of the driver include: having motor insurance with HSE indemnification; ensuring vehicle is road-worthy, taxed and has NCT validation if required. In addition, the policy summarises risk factors associated with driving and include:

- Speeding
- Alcohol and drugs
- Seat belts
- Driver fatigue
- Distracted Driving.<sup>(29)</sup>

Risk assessment regarding fitness to drive is conducted alongside Occupational Health Services. All accidents, incidents and near misses are reported, and managed in accordance with the HSE Safety Incident Management Framework 2018 which was updated in 2020 and renamed Incident Management Framework.<sup>(45)</sup>

### **2.9.3.5 Policy on the Prevention and Management of Work-Related Aggression and Violence, HSE (2018)**

The *Policy on the Prevention and Management of Work-Related Aggression and Violence* begins with a definition of work related aggression that is used by the HSE, that being "any incident where staff are abused, threatened or assaulted in circumstances related to their work, involving an explicit or implicit challenge to their safety, well-being or health."<sup>(29)</sup> The aim of this policy is to ensure resources are available for risk assessment and for appropriate education in the management of aggression and violence. The policy is underpinned by the Safety Health and Welfare at Work Act 2005 and associated regulations. It outlines roles and responsibilities, from the Director General having overall responsibility for ensuring governance arrangements are in place, to National Directors ensuring risk management procedures are in place and line managers and employees ensuring communication and awareness of risk procedures. The policy sets out procedures for risk assessment and risk management whereby contributory factors such as people using services, employees, the interaction taking place, physical and service environments are all involved in a process with risk management. Emphasis is placed on having appropriate systems to manage the identification, evaluation and management of risk. Foreseeable acts of work-related aggression and or violence must be

communicated to all staff, take a multidisciplinary approach to assessment and care planning, with appropriate risk management processes in line with the former HSE Incident Management Framework (2018). Appropriate staffing levels should be in place and on-site security personnel must be informed of the risks and control measures in place to prevent and manage aggression and violence. The policy also describes the responsibility of line managers to support staff who have been exposed to aggression and or violence to support staff wellbeing. In addition, staff can use occupational health services or the Employee Assistance Programme that provide confidential independent advisory service. They also promote physical, mental and social wellbeing of staff.<sup>(29)</sup>

### **2.9.3.6 Occupational Safety and Health and Homecare, Health and Safety Authority (2017)**

This is an information sheet intended for employers and employees providing formal homecare to older and vulnerable people. Homecare is defined as “support provided (both short and long term) to people who require assistance to continue to live independently, outside of a hospital or residential care setting.”<sup>(46)</sup> The information sheet recognises that homecare provision can present unique hazards and risks and hence should be identified and managed. It highlights that the Safety, Health and Welfare at Work Act 2005 places an obligation for employers to manage safety and health at work. The foundation of managing safety and health is written in the safety statement and must be based on the identification of hazards and the assessment of risk. Safety and health management systems are tailored to suit the needs of the service provider. Occupational safety and health issues should be factored in at referral stage, individual assessment of needs stage, assessing the home environment stage, and identification of equipment required. The elements of occupational safety and health set out in this sheet are:

- staff training and development
- supervision of staff
- risk profile and assessment
- manual and people handling
- challenging behaviours and potential for work related violence and aggression
- lone working
- slips, trips and falls
- biological hazards.<sup>(46)</sup>

### **2.9.3.7 Policy on Lone Working, HSE (2017)**

The aim of the *Lone Working Policy* is to ensure the safety of lone workers by reducing potential risks associated with lone working. The policy sets out steps in identifying the risk, implementing control measures and assurance that adherence to such measures occur. Lone workers are defined as “employees who work by themselves without close or direct supervision. They are physically isolated from fellow employees and without access to immediate assistance.”<sup>(22)</sup> The policy applies to all HSE employees. Overall responsibilities are to ensure safety, health and welfare at work for all employees as far as is reasonably possible. Risk associated with lone working needs to be evaluated, managed, monitored and audited. The different roles and responsibilities are described under the director general, assistant national directors, senior managers, line managers, and employees. In addition, the policy sets out an implementation plan underpinned by consultation, communication, supervision, monitoring, audit and review.<sup>(22)</sup>

### **2.9.3.8 Protecting HSE Staff from Second-hand Smoke in Domestic Settings Policy (2014)**

*Protecting HSE Staff from Second-hand Smoke in Domestic Settings Policy* aims to manage and reduce risk to staff and service users who are exposed to second-hand smoke. It is specifically aimed at protecting people who are entering domestic settings. The policy is in response to the HSE’s obligation under the Safety, Health and Welfare at Work Act 2005 to provide a safe working environment for employees. While section 47 of the Public Health (Tobacco) Act 2002 prohibits smoking in the workplace, this does not apply to people’s homes.

Overall, the policy outlines the HSE’s commitment to reduce risk from second hand smoke for staff who work in domestic settings and provides guidance to staff, managers and service users. The policy applies to all employees of the HSE and to agency-employed healthcare staff who provide homecare services under the supervision and control of HSE line management.<sup>(28)</sup>

Responsibilities to implement the policy ranges from the employer, senior managers, line managers, and employees. The policy also places an obligation on service users and other persons present in the home to comply with this policy. It creates an awareness that an employee may leave if they do not comply with the policy. In situations where the service user has a cognitive impairment or exhibits challenging behaviour, there is an expectation that family members will support compliance with the policy. Information is provided to the service user about smoking and protecting the health of the staff by for example, not smoking an hour before the visit, area for the visit is fully ventilated if smoking has taken place, informing the service user that

an alternative venue will have to be arranged if the service user does not cooperate with the request for a smoke free environment.<sup>(28)</sup>

The service user's care plan should have documented the smoking status and if potential for second hand smoke is a risk. It is emphasised throughout the policy that the service user is informed of the policy and regardless of planned or unplanned visits, a request for a smoke free environment should be highlighted to the service user. Non-compliance with the policy should be referred to the line manager and consideration given to alternative venue to provide the service. In addition, staff should complete the HSE risk assessment procedures if deemed necessary. The policy includes an appendix with smoke free information for people receiving home visits.<sup>(28)</sup>

### **2.9.3.9 Dignity at Work Policy for the Health Service, Anti Bullying, Harassment and Sexual Harassment Policy and Procedure (2009)**

The *Dignity at Work* policy states that all employees are entitled to be treated with dignity and respect in the workplace. In addition, employees have a duty of care to treat others with dignity and respect. The overall aim of the policy is to provide protection to employees from incidents of bullying, sexual harassment and harassment. The policy provides explicit definitions and gives examples of bullying, harassment and sexual harassment. It sets out steps that should be taken in the event of a complaint, including the roles and responsibilities of employers, employees, managers and union representatives. Additional steps include having a support contact person, mediation and formal investigation.<sup>(47)</sup>

### **2.9.3.10 Trust in Care, Policy for Health Service Employers on Upholding the Dignity and Welfare of Patient/Clients and the Procedure for Managing Allegations of Abuse against Staff Members (2005)**

The aim of the *Trust in Care Policy* is described as two-fold: one aim is underpinned by preventing harm or abuse by ensuring the highest standards of care among staff; and the second aim is to have proper procedures in place to report and manage allegations of harm or abuse against a staff member. The policy describes a duty of care on all staff to protect patients and or clients from harm or any behaviours that violates dignity. In addition, health services have a duty of care to provide staff with the necessary training, supervision and support to deliver high standards of quality care. The policy defines the term abuse under neglect, emotional and or psychological abuse, physical abuse and sexual abuse and then sets out guidance on

abuse prevention, procedures for receiving a complaint or allegation of abuse, procedures for managing allegations of abuse and then follow-up actions.<sup>(48)</sup>

### **2.9.3.11 HSE Your Service Your Say**

*HSE Your Service Your Say* is the management of feedback for comments, compliments and complaints from people using services. Your service your say applies to all services provided directly by the HSE or through its contractual arrangements with other services. The HSE aims to support a culture of receiving and addressing feedback at local level. This is underpinned by part 9 of the Health Act 2004 that sets out that the HSE provides a system for the management of complaints. In doing so, it also assists staff to respond to feedback. Your service your say has been developed from the *Your Service Your Say, The Management of Service User Feedback for Comments, Compliments and Complaints, HSE Policy 2017* and is structured around five principles:

1. Enabling feedback
2. Listening and responding to feedback
3. Supporting service users
4. Supporting staff
5. Learning, improvement and accountability.<sup>(28)</sup>

### **2.9.4 National Frameworks**

This section describes five national frameworks that set the foundations for developing community services such as homecare and support in Ireland and have acted as catalysts in improving the delivery of safe integrated care. The following frameworks are summarised:

- The Disability Action Plan Framework – Review of Disability Social Care Demand and Capacity Requirements to 2032
- Healthy Ireland – a framework for improved health and wellbeing (2019-2025)
- A National Framework for Person-Centred Planning in Services for Persons with a Disability (2018)
- Outcomes for Disability Services, National Disability Authority (2016)
- Sláintecare (2017)
- Better Outcomes, Brighter Futures: The National Policy Framework for Children and Young People (2014-2020)
- Palliative Care Services, Three Year Development Framework (2017-2019)

### **2.9.4.1 The Disability Action Plan Framework - Review of Disability Social Care Demand and Capacity Requirements to 2032**

The *Review of Disability Social Care Demand and Capacity Requirements to 2032* sets out the future needs for specialist disability social care services in Ireland. The review includes projections of scale and range of the capacity required to meet the needs of disability support services between now and 2032. In doing so, a framework was developed that offers a planned, structured, effective, and efficient approach to meeting the needs of people with a disability requiring specialist social care services. The framework takes into account the rising demographic changes and existing service deficits. In addition, it outlines capital funding to deliver programmes to address these deficits, for example investments of €2.2 billion for HSE-funded disability support services in 2021. The overarching aim is to move away from institutional care towards community based housing and address areas such as: assessment of need; children’s disability network teams; children’s therapy posts; intensive support packages for children and young adults; personal assistance hours; and personalised budget pilot projects. In addition, the review highlighted that the majority of disability services have been COVID-19 free since the beginning of the COVID-19 pandemic.<sup>(22)</sup> The priority areas that the framework plans to deliver on and form part of Sláintecare action items includes the following:

- Children’s Services: Policy: *Progressing Disability Services for Children and Young People Programme (2009)*
- Intensive support packages for young people with disabilities experiencing severe distress
- Day Service places for school-leavers: Policy: *New Directions - Day services for adults with disabilities (2012)*
- Personal assistance and home supports
- Respite services, including alternative respite
- Additional residential care places in the community Policy: *Time to Move on from Congregated Settings* and the *National Housing Strategy for People with a Disability (2011)*.<sup>(22)</sup>

### **2.9.4.2 Healthy Ireland – a framework for improved health and wellbeing**

The *Healthy Ireland – a framework for improved health and wellbeing (2019-2025)* was developed in response to Ireland’s growing and ageing population and an increase in people and families affected by chronic diseases and disabilities attributed to lifestyle choices.<sup>(32)</sup> The framework as displayed in figure three describes a roadmap for building a healthier Ireland, drawn from existing policies

and best evidence. It sets out a vision that describes the value of health and wellbeing to individuals, communities and society as a whole and advocates that every section of society must work together to achieve health and well-being. The vision of a healthy Ireland is:

Where everyone can enjoy physical and mental health and wellbeing to their full potential, where wellbeing is valued and supported at every level of society and is everyone's responsibility.<sup>(32)</sup>

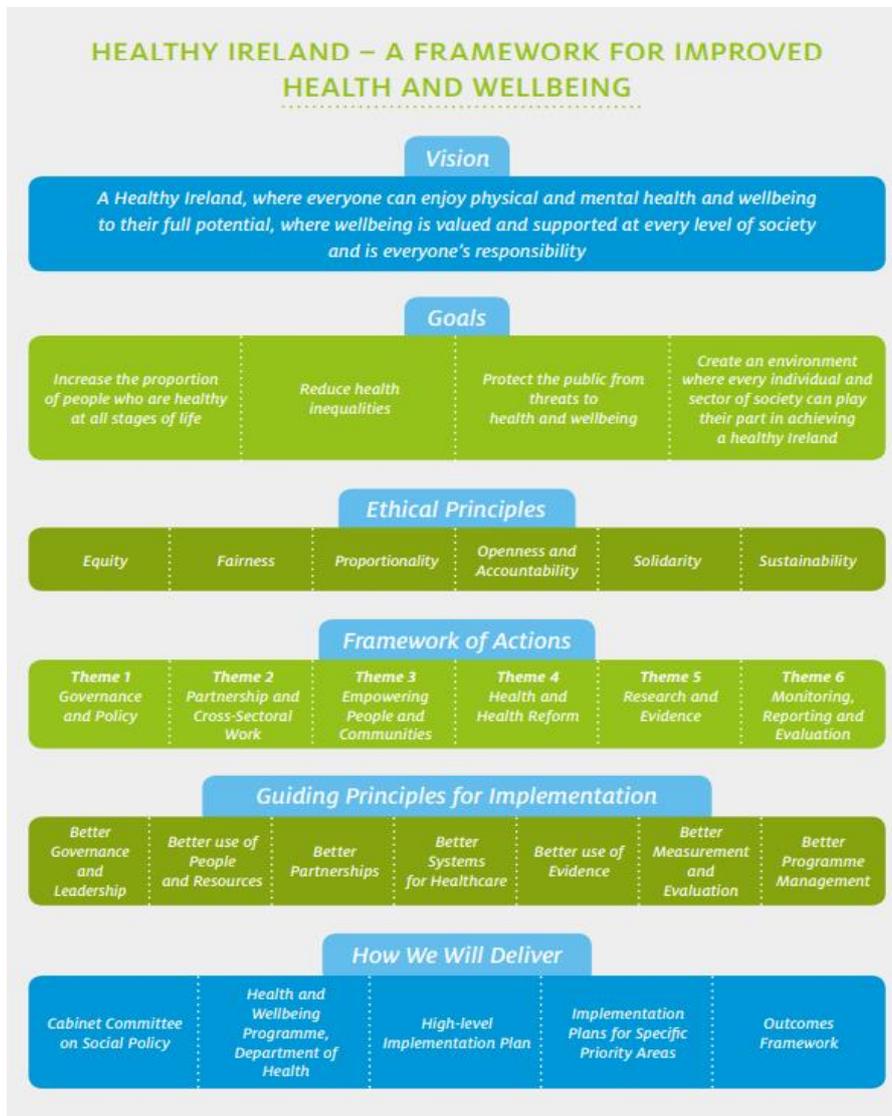
The framework has four goals, all of which are interlinked and interdependent of each other. The four goals of Healthy Ireland are listed as follows:

- Goal 1: Increase the proportion of people who are healthy at all stages of life
- Goal 2: Reduce health inequalities
- Goal 3: Protect the public from threats to health and wellbeing
- Goal 4: Create an environment where every individual and sector of society can play their part in achieving a healthy Ireland.<sup>(32)</sup>

Each goal is underpinned by ethical principles and associated themes that will help achieve the goals of the framework. The themes are relating to the implementation of the goals at government, sectoral, community and local levels. Home support falls under theme three, 'empowering people and communities'. This involves developing strategies and partnerships to facilitate people living in their own homes and communities with confidence, security and dignity for as long as possible.

The Healthy Ireland framework mandated a number of national policy priority programmes to improve health and wellbeing such as the HSE Positive Ageing Programme.<sup>(32)</sup>

**Figure 2.2 Healthy Ireland – A Framework for improved health and wellbeing (2019-2025)**



**Source:** Department of Health (2019). Healthy Ireland – A Framework for improved health and wellbeing (2019-2025).<sup>(32)</sup>

### **2.9.4.3 A National Framework for Person-Centred Planning in Services for Persons with a Disability (2018)**

The national HSE framework for person-centred planning was developed in response to an identified need for more consistent person-centred planning in Ireland. The framework acts as a guidance and is relevant for all services for persons with a disability, including day care services, residential care centres and home and community services that are HSE funded supports through disability funded services.<sup>(49)</sup>

The aims of the framework are to:

- support the achievement of positive outcomes for persons with a disability
- support individuals and teams to consistently deliver good practice in person centred planning
- foster an ongoing commitment to person-centredness and person-centred planning
- identify the key beliefs and foundations which are at the centre of good person-centred planning
- embed and sustain the main elements of good practice in person-centred planning
- encourage individuals, staff teams and managers to evaluate and critically reflect on their organisation's policies and practice in relation to person centred planning
- make practical recommendations to support effective person-centred planning
- identify tools and resources that support good practice.<sup>(49)</sup>

The framework was informed by a review of the literature following on from the *National Disability Authority (NDA) Guidelines on Person-centred Planning in the Provision of Services for People with Disabilities in Ireland*, published in 2005. In addition, it was informed by an examination of person-centred plans alongside interviews and an analysis of HIQA inspection reports. It is emphasised in the framework that the user must ensure that each statement of practice is meaningful to the person and their context. Subsequently, services and supports are tailored to the individual needs of the person. The aim of person-centred planning is to support and enable a person to make an informed choice about how they want to live their life and encompasses identifying their dreams, wishes, and preferences. It is imperative that the person-centred planning process is accessible to the person and that all information is provided in a format that is meaningful to the person. A personalised care and support plan covers the range of different supports that respond to a person's day-to-day needs and preferences. Applying a rights-based approach is embedded in person-centred planning and is described as beliefs that

should be adopted at all stages of the planning. The beliefs are listed alongside descriptions as follows:

- **Individuality:** each person is an individual with their own life experience, skills, gifts, talents and culture.
- **Equality:** each person with a disability has the same rights as all others in society. Each person is given information and support to understand and claim their rights.
- **Respect:** each person is treated as an adult. Relationships are built on respect.
- **Dignity:** the privacy and dignity of each person is respected. Each person with a disability is given the chance to take risks and try new things.
- **Empowerment:** person-centred planning supports the person to take control of their life. Each person is supported to have their say and their views are respected.
- **Choice:** everyone is given the chance to make choices and decisions about their person-centred plan and about their lives. Individuals are supported to communicate their choices and decisions.
- **Inclusion and active citizenship:** each individual is an important member of their community, trusted to hold valued social roles. Person-centred plans support the person to take part in their community, to make new friends and have new experiences.
- **Independence:** each person is supported to be as independent as they can be.<sup>(49)</sup>

The framework is made up of four stages in person-centred planning (Figure 2.2):

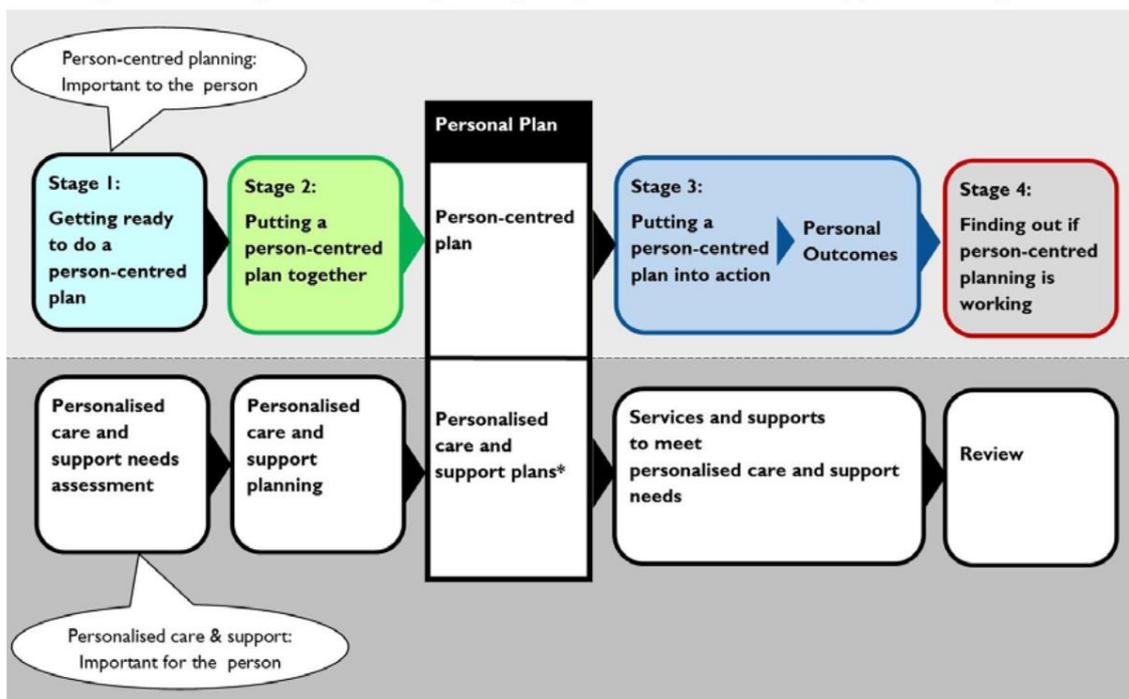
- Stage 1 - Getting ready to do a person-centred plan
- Stage 2 - Putting a person-centred plan together
- Stage 3 - Putting a person-centred plan into action
- Stage 4 - Finding out if person-centred planning is working.

Each stage is described and some examples of case studies are provided. Person-centred planning practices are provided in order to help services determine any planned changes and actions. An evaluation process is used to assess implementation of the framework and includes feedback from the person who owns the person-centred plan, their family and support staff. Feedback is based on their experiences of engagement in person-centred planning and can be obtained through various methods such as: conversations with people using services, families and staff through dialogue, focus groups, face-to-face meetings; active learning sessions using reflection; and staff support and mentoring sessions and surveys. The

intended outcome from implementing a person-centred plan is that the person at the centre of the planning process has experienced a real change for the better in their life.<sup>(49)</sup>

### Figure 2.3: The four stages in care planning

Figure 1.3. How person-centred planning and personalised care and support work together



\*Personalised care and support plans should be developed within 28 days of a person starting to use a HIQA-registered residential service. Person-centred planning may take considerably longer, depending on the individual.

**Source:** HSE (2018). A National Framework for Person-Centred Planning in Services for Persons with a Disability.<sup>(49)</sup>

The HSE has a dedicated webpage with resources and tools to support the implementation of the Person-Centred Planning Framework. These include a series of webinars, Easy-to-Read Person Planning Framework and guidance documents.<sup>(50)</sup>

#### 2.9.4.4 Outcomes for Disability Services, National Disability Authority (2016)

The National Disability Authority (NDA) published a report drawing on research conducted on outcomes measurement for the delivery of person-centred disability services. Outcomes measurement shifts the focus from undertaking activities and service delivery to measuring the impact of those activities for people using services. The many reasons why outcomes are important include:

- accountability to people with disabilities, their family and the wider public
- the HSE as the commissioner and funder of services needs to know what outcomes individual services are achieving
- managers of services need to know what outcomes their service is achieving and use the outcomes as a benchmark against other services
- knowledge of outcomes that people with disabilities are achieving, taking into account public financial investments.<sup>(51)</sup>

The report highlights that outcome measurements is not an isolated project, but one that forms part of larger programme of reform encompassing standards and quality initiatives making up a wider outcomes framework.<sup>(51)</sup>

The NDA developed a set of outcomes in consultation with people with intellectual disabilities, physical and sensory disabilities. The report presents a table of these proposed outcome measures and sub-domains covered under the outcome, followed by an abbreviation or short description of each outcome (see Table 2.4) The outcomes described in Table 2.4 closely match outcome frameworks from international evidence, quality frameworks for disability services, standards for residential and day services and the United Nations Convention on the right of Persons with Disabilities (UNCRPD). The outcomes are aligned to best practice, for example, the outcomes relate to models of quality of life and wellbeing such as the UNCRPD principles and wellbeing models set by the National Economic and Social Council (NESC) Report in Ireland.<sup>(51)</sup>

Feedback from consultations highlighted the importance of interdependency and personal relationships, including more choice and control. In addition, outcome measurements used internationally were reviewed, for example, outcome measures that were piloted for Australia's statutory National Disability Insurance Scheme, were examined. Outcomes measurement also align with National Standards such as the National Standards for Residential Services for Children and Adults with Disabilities.<sup>(52)</sup> The NDA is currently examining potential indicators for each outcome statement, drawing on international suites of life indicators, perspectives from people with disabilities' of what outcomes should be achieved, existing data from national surveys and HIQA inspections.

**Table 2.4: Full proposed list of outcome measures**

	<b>Outcome</b>	<b>Sub-domains</b>	<b>Abbreviation</b>
	Disability service users:		
1.	Are living in their own home in the community	Ordinary housing Suitable housing (e.g. adapted) Choice of who lives with	Living in the community

		The run of your home Privacy	
2.	Are exercising choice and control in their everyday lives	Choice Control Everyday routines Major life decisions Positive risk-taking	Choice and control
3.	Are participating in social and civic life	Social life Socially connected/not lonely Community activities Civic activities Can access the community (accessibility/transport/mobility) Attends church if so wishes	Social and civic participation
4.	Have meaningful personal relationships	Family Friends Intimate relationships	Personal relationships
5.	Have opportunities for personal development and fulfilment of aspirations	Education Training Education/training outcomes Realisation of personal goals, both long-term and short-term	Education and personal development
6.	Have a job or other valued social roles	Employment Other valued social roles Doing things for others	Employment and valued social roles
7.	Are enjoying a good quality of life and well being	Satisfaction with life	Quality of life
8.	Are achieving best possible health	Physical health Mental health Healthy lifestyle Preventive care	Health and well-being
9.	Are safe, secure and free from abuse	Safety Security and continuity Being respected, listened to Freedom from abuse	Safe and secure

**Source:** NDA (2016). Outcomes for Disability Services.<sup>(51)</sup>

#### **2.9.4.5 Sláintecare (2017)**

The Oireachtas Committee on the Future of Healthcare developed the *Sláintecare* report that sets out a 10-year strategic framework to reform the Irish health system. The *Sláintecare* vision is to get “the right care, in the right place, at the right time”.<sup>(7)</sup> This will be achieved by having a universal single-tier health and social care

system, where everyone has equal access to services based on need, and not ability to pay. *Sláintecare* has achieved political cross-party agreement on a single, long-term vision for health and social care and the direction of health policy in Ireland. The report refers to home support as “homecare” and discusses the implications of austerity measures on homecare services in Ireland, highlighting reductions in people receiving home help and reductions in home help hours provided to people in the years preceding the report. Recommendations set by the Committee pertaining to homecare services include universal access to primary care, homecare and expanding homecare services. It highlights the current inconsistencies in homecare packages due to availability of services and geographical variations.<sup>(7)</sup>

The Committee engaged with advocacy groups, such as groups representing people with disabilities and older people, when developing this report and concerns expressed were in relation to inadequate provision of homecare services. It was reported that if homecare and support was a statutory service, this would enable people to live longer at home and more independently. Public bodies would have to develop, fund, plan and make available a comprehensive home support service and this would facilitate more timely discharges from hospitals. A strong theme reported from the advocacy groups was a need to put in legislation that homecare is a statutory entitlement. The report provides key recommendations for social care expansion and includes increasing homecare provision and allocating an additional €120 million for homecare in the first five years of the implementation of the *Sláintecare* programme. In addition, the report recommended allocating €290 million for services for people with disabilities over a ten year period.<sup>(7)</sup> As part of the *Sláintecare* implementation strategy, the Irish government committed to introducing a statutory scheme for homecare by 2021.

#### **2.9.4.6 Better Outcomes, Brighter Futures: The National Policy Framework for Children and Young People 2014 – 2020**

*Better Outcomes, Brighter Futures: The National Policy Framework for Children and Young People 2014 – 2020* was developed by the formerly-known Department of Children and Youth Affairs (DYCA) in Ireland. The framework is a Government-wide national policy framework for children and young people aged 0-24 years. Its purpose is to coordinate policy and action across government departments and statutory and non-statutory services working with children and young people to achieve better outcomes for all children.<sup>(53)</sup> The framework describes a vision for:

Ireland to be one of the best small countries in the world in which to grow up and raise a family, and where the rights of all children and young people are respected, protected and fulfilled; where their voices are heard

and where they are supported to realise their maximum potential now and in the future.<sup>(53)</sup>

The policy framework recognises that some children and families may be more at risk than others, due a range of factors including socio-economic issues, family difficulties and enduring health conditions. To achieve positive outcomes, *Better Outcomes, Brighter Futures* seeks to make sure that services are integrated and provide a continuum of care supports and interventions for 'at-risk' children and young people and their families, in partnership with other statutory and community services. It sets out five national outcomes underpinning policy for children and young people across government. These outcomes include that children and young people:

- are active and healthy and have positive physical and mental wellbeing
- achieve their potential in terms of learning and development
- are safe and protected from harm
- have economic security and opportunity
- are connected, respected and contribute to their world.

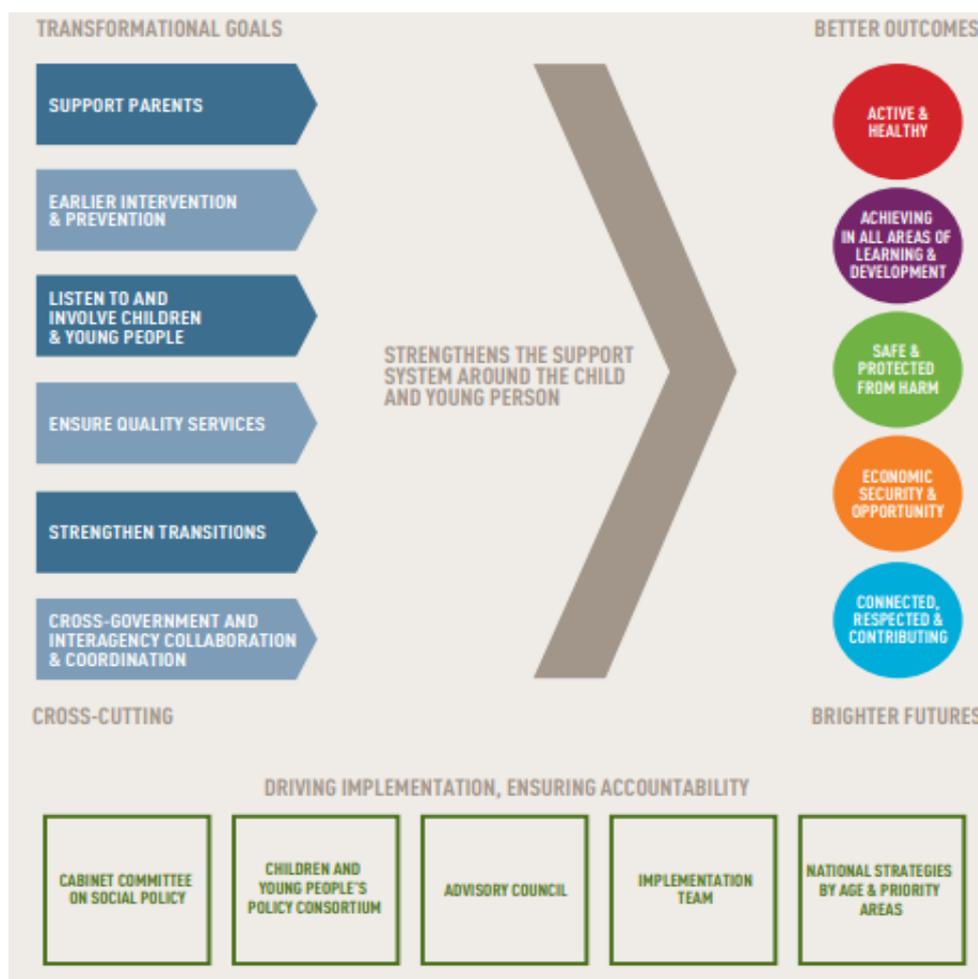
To achieve these outcomes, there are six transformational goals described as being key to transforming the effectiveness of existing policies, services and resources for children and young people. These transformational goals are:

- support parents
- earlier intervention and prevention
- a culture that listens to and involves children and young people
- quality services – outcomes-driven, effective, efficient and trusted
- effective transitions
- cross-government and interagency collaboration and coordination.

The outcomes and transformational goals are displayed in Figure 2.3 as presented in the framework document. To achieve both the outcomes and the transformational goals *Better Outcomes, Brighter Futures* recognises the need for services to work in partnership with children, families and community and to build on their strengths. The policy framework highlights the importance of strategic leaders who build a culture of collaboration and communication within their organisation and with communities, and it recognises the need for these leaders to support their staff and volunteers to work to achieve the outcomes of the national strategy. While there is not a direct reference made to home support services for children in the framework, a strong theme across the framework is building secure, stable, supportive and caring home environments. Government commitments include building on

Community Nursing Services and family support provision (including home visiting).<sup>(53)</sup> However, *Better Outcomes, Brighter Futures* was reviewed in 2018 and findings reported a low level of awareness at community and individual level of the purpose and strategic objectives of the framework.<sup>(54)</sup>

**Figure 2.4: A Policy Framework for Improved Outcomes for Children and Young People**



**Source:** DYCA (2018). *Better Outcomes, Brighter Futures*.<sup>(53)</sup>

#### **2.9.4.7 Palliative Care Services, Three Year Development Framework (2017-2019)**

The *Palliative Care Services, Three Year Development Framework* sets out to inform and direct the development of palliative care in Ireland over a three year period. The overarching aim is to provide a quality palliative care service that meets the needs of individuals and their families in all care settings. It strives to ensure a "seamless care pathway across inpatient, homecare, nursing home, acute hospital and day care

services.”<sup>(22)</sup> The framework is structured around the five corporate goals set out in the HSE Corporate Plan 2015-2017. Section three of the framework discusses generalist Palliative Care and addresses homecare whereby there has been a phased introduction of Community Intervention Teams. The aim of these teams is to support the transition of palliative care patients from hospital to home. Carers should be supported by having more home help hours, quicker access to equipment and community therapists, more available information on supports and services, and access to respite care both outside and in the home. In addition, carers have reported feelings of isolation when caring for a relative at home and the inability of neighbours and friends to express their support. The framework recommends that the HSE should support initiatives, for example public awareness campaigns, to raise public awareness and to change the culture around death and dying. Section four discusses Specialist Palliative Care and recommends that patients be discharged home from hospital as soon as their condition allows and recommends the use of the *Rapid Discharge Guidance for People Who Wish to Die at Home* developed by the National Clinical Programme for Palliative Care. The framework calls for an agreed understanding of roles and responsibilities between public health nursing and specialist palliative care, with an aim for collaboration and integration of nursing services in the community.<sup>(22)</sup>

### **2.9.5 National Strategies**

This section describes national strategies that have the provision of homecare and support deeply embedded in its vision and policy for Ireland’s population. The following strategies are summarised in this section:

- National Disability Inclusion Strategy 2017-2021
- National Dementia Strategy 2014
- National Positive Ageing Strategy 2013
- National Carers’ Strategy 2012.

#### **2.9.5.1 National Disability Inclusion Strategy 2017-2021**

The *National Disability Inclusion Strategy* was developed by the Department of Justice and Equality and is underpinned by the Disability Act 2005. The overall aim of the strategy is to promote greater inclusion by people with disabilities in community life. It is a whole-government approach, requiring the integration and coordination of different government departments and public organisations such as the Mental Health Commission and dedicated disability services to work in partnership to improve the lives of people with disabilities. The strategy comprises of eight overarching themes, with 34 outcome statements and 114 actions, with

timescales to deliver on these outcomes. The themes set out in the strategy are as follows:

- equality and choice
- joined-up policies and public services
- education
- employment
- health and wellbeing
- person-centred disability services
- living in the community
- transport and accessible places.

The themes most relevant to homecare and support services are 'person-centred disability services' and 'living in the community'. Actions include a shift away from a 'care' model to a 'support model' that will maximise independence for people with disabilities. There is a focus on empowering people by giving autonomy to make choices and have control over their own lives and where they choose to live in local communities. A government vision is one that will reduce and even close congregated settings. In addition, actions are set out to work with local authorities on housing schemes and adaptations to homes so they are accessible and usable by all persons irrespective of size, age, ability or disability.<sup>(55)</sup> A National Disability Strategy Implementation Group was tasked with monitoring the implementation progress and outcomes achieved under the strategy. The group members are senior officials from government departments, the National Disability Authority, Disability Stakeholder groups, and individuals with experience of living with a disability. A review conducted by the Department of Justice and Equality in 2020 on the outputs to date from the National Disability Inclusion Strategy highlighted some significant changes for people with disabilities in Ireland but more notable changes relating to home support include the following:

- The ratification by Government of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2018. The UNCRPD sets out key rights for people with disabilities so they are treated equally and consulted actively on policy and have autonomy in life choices and decisions
- A reduction from approximately 4,000 people with disabilities living in congregated type settings in 2016 to less than 2,100 in 2020
- The development of a protocol between disability services and mental health services by the HSE to ensure appropriate access to mental health services for persons with disabilities

- A report of the Personalised Budgeting Task Force that describes how personalised budgets can work for people with disabilities and offer them greater choice and control over the services and supports they receive.<sup>(56)</sup>

### **2.9.5.2 National Dementia Strategy 2014**

The aim of the *Irish National Dementia Strategy* is to improve dementia care so that people with dementia can live well for as long as possible and can have services and supports delivered in the best way possible. The strategy uses guiding principles to underpin health and social care services that are provided to people with dementia, their families and carers.<sup>(57)</sup> It also identifies six priority areas for action and they are:

- better awareness and understanding
- timely diagnosis and intervention
- integrated services, supports and care for people with dementia and their carers
- training and education
- research and information systems
- leadership.<sup>(57)</sup>

Objectives set pertaining to homecare and support fall under the priority areas for better awareness and understanding, and integrated services. Key objectives include building dementia-friendly communities and improving quality of care in the home. Commitments are made to invest in homecare packages and respite care to facilitate people with dementia to continue living in their own homes and communities and to improve supports for carers. The important role that homecare packages play in supporting people with dementia to live at home safely and for a longer time, is highlighted in this strategy. Additional actions include work by the Department of Health on proposals for the regulation of home and community care services and promoting a roll-out of the carer's assessment component of the SAT.<sup>(57)</sup>

In response to the National Dementia Strategy, the *HSE and Genio Dementia Programme* was established to develop a new service model to improve community-based supports for people with dementia, one of which was the provision of Intensive Homecare Packages for people with Dementia.<sup>(22)</sup>

### **2.9.5.3 National Positive Ageing Strategy 2013**

The National Positive Ageing Strategy is described as 'citizen-centred' and begins with a key message highlighting that an ageing population is one that reflects success and opportunities for economic, social and cultural growth.<sup>(58)</sup> The strategy

calls for a change in mindset from a stereotypical viewpoint of ageing, that older people are frail, sick or disabled and dependent on the welfare system, to one that views older people as healthy and having financial security.<sup>(58)</sup> The principles underpinning the strategy are the United Nations Principles for Older Persons and are listed as independence, participation, care, self fulfilment and dignity.<sup>(58)</sup> Four national goals were developed to address important aspects of older people's lives and have related underpinning objectives. National goals number two and three address the area of home support and state the following:

- National Goal 2: Support people as they age to maintain, improve or manage their physical and mental health and wellbeing.
- National Goal 3: Enable people to age with confidence, security and dignity in their own homes and communities for as long as possible.<sup>(58)</sup>

Objectives underpinning these national goals include:

- Promoting the development and delivery of a continuum of high-quality care services and supports that are responsive to the changing needs and preferences of people as they age and at end of life.
- Facilitating older people to live in well-maintained, affordable, safe and secure homes, which are suitable to their physical and social needs.
- Empowering people as they age to live free from fear in their own homes, to feel safe and confident outside in their own communities, and support an environment where this sense of security is enhanced.<sup>(58)</sup>

The strategy affirms governmental policy to support older people to live as independently as possible in their own homes and communities and highlights the important role that home help and homecare packages play in supporting government policy and people to stay at home.<sup>(58)</sup>

#### **2.9.5.4 National Carers' Strategy - Recognised, Supported, Empowered 2012**

The *National Carers' Strategy: Recognised, Supported, Empowered* aims to reflect the government's recognition and respect for carers as key care providers for older people, children and adults with an illness or a disability. The aim is to support people to live with dignity and independence in their own homes and communities for as long as possible.<sup>(59)</sup> The guiding principles underpinning the strategy are recognition, support and empowerment. It provides an implementation roadmap to deliver on the national goals and objectives that include achieving a work-life balance, involvement in decision-making and ensuring that the views of carers as

well as the people they care for are taken into consideration during assessment of needs.<sup>(59)</sup> There have been calls from carers' advocacy groups to renew this strategy and focus on an appropriately funded one. It has been argued that the *National Carers' Strategy* was developed during a time of austerity and hence was a cost neutral strategy.<sup>(60)</sup>

## 2.10 Findings from reviews

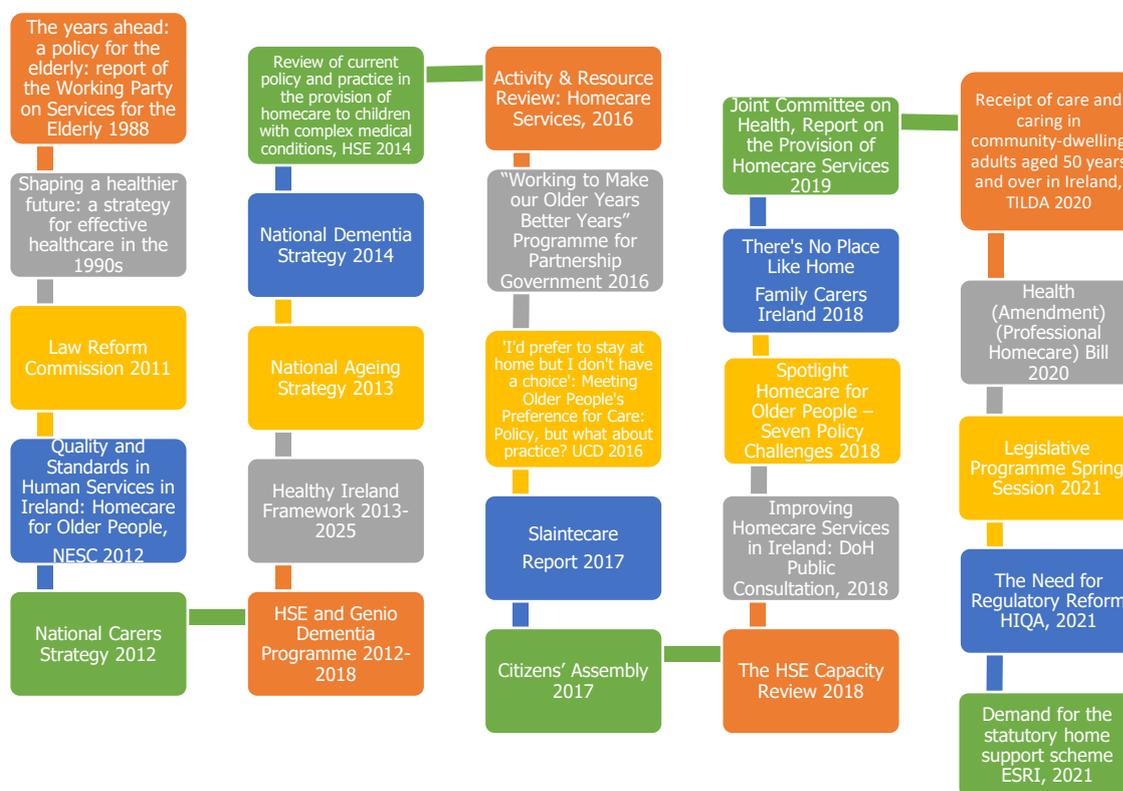
There is an array of reviews, reports and recommendations across the Irish literature that examine homecare. They are all evident of the long-standing support for reform of the Irish homecare and support sector. Figure 5 displays a summary of this literature from government, policy-makers, researchers and advocacy groups dating back as far as the 1980s.

The following reports and reviews have been selected for discussion due to their relevance to homecare and support; their up-to-date information; suggestions by respondents to HIQA's scoping consultation as key sources of information to inform the development of national homecare and support standards.

The reports and reviews discussed herein are:

- Disability Capacity Review to 2032, A Review of Disability Social Care Demand and Capacity Requirements up to 2032.
- Information and Communications Technology (ICT) Enablement of Older Persons Services (2021-2022)
- Regulation of Homecare: A Position Paper (HIQA, 2021)
- The Need for Regulatory Reform (HIQA, 2021)
- Care experiences and homecare preferences amongst older Travellers and older people experiencing homelessness. A briefing paper based on the Older Traveller and Older Homeless (OTOH) study (2021)
- An inquiry into the lived experience of Covid-19 in the homecare sector in Ireland, the experiences of homecare provider organisations (2020).
- Report of the Policy Dialogue on the New Homecare Scheme (2020)
- COVID-19 Nursing Homes Expert Panel: Examination of Measures to 2021 - Report to the Minister for Health (2020)
- Joint Committee on Health, Report on the Provision of Homecare Services (2019)
- Improving Homecare Services in Ireland: An Overview of the Findings of the Department of Health's Public Consultation (2018)
- Improving homecare services in Ireland Home and Community Care Ireland (HCCI) (2018)
- HSE and Genio Dementia Programme 2012-2018

- Developing and Implementing Dementia Policy in Ireland (2017)
- A National Model of Care for Paediatric Healthcare Services in Ireland  
Chapter 18: Community Services for Children with Ongoing Health Needs (2016)
- Access to Life: Personal Assistant Services in Ireland and Independent Living by People with Physical and Sensory Disabilities (2014)
- Quality and Standards in Human Services in Ireland: Homecare for Older People, National Economic and Social Council (2012)

**Figure 2.5: Summary of Irish literature pertaining to Home Support in Ireland 1988-2021**

**Source:** Various sources (1988-2021). HSE, HIQA, ESRI, Genio, and the Department of Health.

### 2.10.1 Disability Capacity Review to 2032 - A Review of Disability Social Care Demand and Capacity Requirements up to 2032, Department of Health

The report *Disability Capacity Review to 2032* was published as part of the *Sláintecare* action plan. The report sets out an analysis of disability support services in Ireland.<sup>(61)</sup> It gives projections of the future size and age-structure of the disability population in Ireland up until 2032 and the scale of unmet needs. In addition, the review examines demographic change, disability services and their expenditure requirements including personal assistance and home support. Just under 11,000 people with a disability currently receive Home Support or Personal Assistant (PA) hours, with approximately twice as many hours given in the form of Home Support.

Approximately 2,500 people get a PA service averaging around 12 hours a week, and around 8,000 people get home support hours averaging around 7 hours a week. People with intellectual disabilities account for around one in four home support recipients, while those with physical, sensory or neurological disabilities make up the balance. Personal assistance services support people with physical, sensory or neurological disabilities. It has not been practice by service providers or the HSE to record unmet needs for home support or PA services and hence no data exists to quantify unmet needs. However, it is reported overall, there are considerable shortfalls in these services relative to need.<sup>(61)</sup> In addition, further costs associated with demographic change for home support, homecare and personal assistance services are estimated at €4 million a year by 2022, €10m a year by 2027, and €15m a year by 2032.<sup>(61)</sup>

## **2.10.2 Information and Communications Technology (ICT) Enablement of Older Persons Services**

At the time of writing, HIQA was developing Recommendations to the Minister for Health on ICT Enablement of Older Persons Services, in response to the COVID-19 Nursing Homes Expert Panel's recommendation for an integrated IT system.<sup>†</sup> These Recommendations outline how best to provide the capabilities outlined by the Expert Panel's recommendation to develop and introduce an integrated IT system for older persons' services, without the requirement that they be delivered by a single system.<sup>(62)</sup> The Recommendations are also aligned to broader national goals under Slaintecare. The aim of the Recommendations remains to make the appropriate information available, safely and effectively, to all treating health professionals across the older person's patient journey, including home support.

### **2.10.2.1 As is Analysis - Information and Communications Technology (ICT) Enablement for Older Persons**

To inform development of the Recommendations, an 'As Is Analysis' was undertaken. For more than a decade, the ultimate aim of national health policy has been the development of a population-based, integrated care model, where care is provided to older persons (and other populations) at the lowest level of complexity and as close to their homes and communities as possible. Therefore, the As Is Analysis briefly examines the national strategic policy framework and the supporting structural, service, and other reforms that are underway as part of Sláintecare and other related policies.<sup>(63)</sup>

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<sup>†</sup> In this context, ICT enablement is used to indicate the provision of appropriate ICT and eHealth solutions to support the safe and effective delivery of health and social care services.

The As Is Analysis also briefly outlines work by national clinical and integrated care programmes. Specific to older persons services, the HSE National Clinical Programme for Older People (NCPOP) developed the acute model of care for frail older people, making recommendations that follow the patient journey from their home, through primary care, acute care and discharge home. It also recommended the InterRAI assessment as the national standard for care needs assessment.<sup>(63)</sup>

Building on the work of NCPOP also, the Integrated Care Programme for Older Persons (ICPOP) developed a national model of service delivery for older persons services with appropriate ICT enablement. This encompasses the provision of home care services. Though ICPOP pilot implementations had some limitations, findings showed the need for shared record functionality, case management functionality, care planning and other capabilities.

ICT is considered to be a crucial enabler of the integrated care model and national infrastructure, such as the national messaging broker, which was also developed while national eHealth strategic programmes were established to ensure the development of a national electronic health record. The Sláintecare Vision provided a comprehensive national vision for an integrated care model, while the Sláintecare Implementation Plan outlined the means for realising this vision, including eHealth as a pillar and national electronic health records as a core enabler.<sup>(6, 7)</sup> The long-term goal was to provide a longitudinal record of a patient's health and social care over their lifetime.

Since the pandemic, the HSE has prioritised the resourcing of primary and community care, and is also prioritising the delivery of basic functionality to support the delivery of formal care services to all populations in the community, including older persons. The As Is Analysis briefly describes this functionality, known as the 'ICT Spine'. It includes the Integrated Community Case Management System (ICCMS), providing case management functionality, and three specialist systems in the areas of home support, residential care, and the InterRAI Assessment. The Integrated Home Support Management system is part of a new overarching approach across rehabilitation, re-enablement, intermediate care and other models of care. The national strategic eHealth programmes are also being progressed.

Finally, the As Is Analysis looks at examples of ICT enablement across different roles and settings.<sup>(63)</sup> It notes the high levels of ICT enablement among GPs but the (typically) lower levels among public sector health and social care professionals providing services to older persons. It also identifies key concerns even in areas of high ICT enablement, owing to the fragmentation of an individual older person's record across different systems.

Thus, the As Is Analysis takes account of the excellent work in the many initiatives and projects that are already ongoing, especially in the HSE. But it also notes gaps – for example, current work is principally intended for the public sector use (in line with the HSE's remit) and there is no published long term strategy, vision or roadmap to show, for example, how the ICT Spine and national eHealth solutions will interoperate. Key findings showed the need for an overarching strategy and governance structures across the transformation of older persons services, public and private, as part of the wider transformation of service delivery across all populations. Other findings indicated the need for an up-to-date national eHealth strategy and for national direction on eHealth.<sup>(63)</sup>

This reflects the findings of the Need for Reform of Ireland's National Health Information System, a 2021 position paper which outlined deficiencies in the national health information system and recommended measures to remedy same. Areas covered in the position paper include: strategy, strategic leadership and governance, legislation, workforce, standards and interoperability, and infrastructure and security.

### **2.10.2.2 Draft for Consultation – Recommendations on ICT Enablement of Older Persons Services**

Together with the findings of the review of international best practice,<sup>(64)</sup> the findings of the As Is Analysis informed the development of Draft Recommendations for Consultation.<sup>(5)</sup> In addition, HIQA convened a special Advisory Group from across the domains of health and social care, and of ICT enablement. Membership was drawn from: policy units and technology specialist units in the Department of Health; from a range of programmes in the Clinical, Information, Operations, and Strategy organisations in the HSE; and from a range of other representative bodies.

Made available for consultation during March and April 2022, the Draft Recommendations outline a number of measures intended to ensure the effective ICT enablement of services for older persons and for other cohorts and populations. The 18 recommendations were grouped into four themes:

- **Strategy and governance:** covering the need for an overarching strategy, at the national level, with full engagement of the public and private sector in the ICT enablement of health service delivery, in line with national policy and the Sláintecare vision. The need to identify an appropriate overall governance structure(s) to identify and implement same was also recommended.
- **Vision and roadmap:** showing the need for a clear vision for the overall ICT enablement of older persons' services should also be developed for the short, medium and long term and for a stakeholder mapping across the public and private sectors. A roadmap was also considered essential.

- **Standardised sharing of information:** highlighted the need for the standardised sharing of information through the analysis of actual information needs of healthcare professionals and the collaborative development of national standards, aligned to the longer term goal of near-realtime sharing of data.
- **User engagement:** noting the need for ongoing involvement of core user groups, in both public and private sectors, and the incorporation of basic principles of user-centred design. Comprehensive self-paced training was also considered necessary, as well as broader initiatives for upskilling nationally.<sup>(5)</sup>

At the time of writing, responses to the public consultation were being analysed and the draft recommendations amended appropriately. Following final comment from the Advisory Group and the approval of the HIQA Board, the final recommendations will be submitted to the Minister of Health.

### 2.10.3 Regulation of Homecare: A Position Paper (HIQA, 2021)

HIQA published a report on *Regulation of Homecare: A Position Paper* in 2021 that sets out HIQA's position on the future of regulating homecare services in Ireland.<sup>(9)</sup> This report was published in conjunction with a review of the current homecare landscape both nationally and internationally and is entitled *Regulation of Homecare: Research Report*. The position paper provides a summary of findings from the *Regulation of Homecare: Research Report*. Key points reported include that legislation, regulations and standards relating to homecare should be underpinned by the principles of a human rights-based approach, safety and wellbeing, responsiveness and accountability. The evidence highlighted that structure, process and outcomes are essential elements to a well-led, quality homecare service. Structures are referred to as the components of the organisation, for example informal carers, assessment systems, staff competence and development. Process is referred to as actions that are carried out for example, care planning, partnerships and communications. Outcomes are referred to as the outputs for a person using homecare services, for example, health promotion, autonomy and control. Based on the evidence, HIQA recommends priority areas for the regulation of homecare services in Ireland. These priorities are as follows:

- be inclusive to all who are in receipt of formal homecare
- improve the performance and quality of homecare
- provide assurance to people receiving homecare and the public that minimally acceptable standards are achieved
- provide accountability on both performance and value for money.<sup>(9)</sup>

Finally, the report presents three options available for the future of homecare services in Ireland: Option one encompasses the current landscape continuing as is; Option two is where the HSE continues to develop and expand services to match the needs of the population; and Option three is to develop a national framework that will mean homecare is available to everyone who needs homecare and age is not a barrier to accessing homecare. Homecare services form part of an integrated service that also supports enablement and independence. HIQA recommends option three but also acknowledges the challenges to implement this option. However, the long-term benefits will outweigh these challenges and ultimately connect with Sláintecare's vision of "the right care, in the right place, at the right time".<sup>(9)</sup> The report provides 13 key areas that HIQA feels need to be addressed and kept at the forefront of decisions pertaining to the home care sector. These key areas are listed as follows:

- **Key area 1:** A 'root and branch' review of homecare from the bottom up
- **Key area 2:** Identify the scope and parameters of homecare
- **Key area 3:** There is a need for homecare to be integrated and needs led
- **Key area 4:** Quality is central to homecare
- **Key area 5:** A national standardised assessment instrument is required
- **Key area 6:** Investment in homecare workers is required
- **Key area 7:** Funding for accessing homecare should be a statutory right
- **Key area 8:** A universal methodology for commissioning disability homecare services should be developed
- **Key area 9:** Homecare must be inclusive, continual and consistent
- **Key area 10:** There needs to be a focus on information sharing using integrated ICT systems
- **Key area 11:** Regulation should only be viewed as one component of broader reform and should not be burdensome
- **Key area 12:** There is a need to focus on maintaining a standard across the homecare sector before driving quality improvement
- **Key area 13:** There is a need to undertake an assessment of the effectiveness and cost-effectiveness of health technologies in homecare in the Irish context.<sup>(9)</sup>

#### **2.10.4 The Need for Regulatory Reform (2021)**

HIQA published a report on the *Need for Regulatory Reform* in 2021 that summarises HIQA's experience of regulating social care services and why change is needed to make regulation fit-for-purpose into the future.<sup>(8)</sup> The report highlights the current challenges and changes occurring in social care in Ireland. The provision of homecare and support services in Ireland is described and the lack of formal

regulation is discussed. The term homecare is used to describe homecare and support services and is defined as follows:

Homecare is the provision of one-to-one care and support services provided by trained staff in a service user's home. Homecare seeks to support people to remain living in their homes by providing assistance with activities of daily living.<sup>(8)</sup>

The report outlines the challenges faced by the homecare sector, for example the lack of statutory entitlement to formal homecare and variation in access to homecare services. Emphasis is placed on the need for investment in homecare regulation to ensure the capacity and capability to deliver care that meets the needs of the Irish population.<sup>(8)</sup>

Other types of services falling under social care are listed as supported and or assisted living and sheltered, home-sharing, respite, short-stay or convalescence or step-down units, hospice and or palliative care and live-in services. The report indicates that, national policies to phase out congregated residential settings and to provide a more person-centred care approach in community settings, have resulted in some services being similar to assisted-living or homecare services. These services are not currently regulated and do not offer the same protections to people who use these services. Moreover, people transitioning into these types of services will be moving from an environment that is regulated into one which is not. In addition, these services do not fall under the current definition of designated centres as set out under the Health Act 2007 and hence, are not regulated.<sup>(8)</sup>

#### **2.10.5 Care experiences and homecare preferences amongst older Travellers and older people experiencing homelessness - A briefing paper based on the Older Traveller and Older Homeless (OTOH) study (2021)**

*Care experiences and homecare preferences amongst older Travellers and older people experiencing homelessness* is a study conducted by the Irish Centre for Social Gerontology that explored the experiences, views and perspectives of older Travellers and older adults who have experienced homelessness in using health and social care services and investigated their needs and preferences relating to homecare delivery.<sup>(65)</sup> The overarching aim is to place the voices of minority groups at the centre of homecare in order to achieve an ethical and rights-based approach to homecare support. This study collected data from focus group discussions with older adult Travellers, older homeless people, stakeholders working with and representing older adult Travellers and older homeless adults. The term 'older' is

defined as aged over 50 years to correspond with the rate of biological ageing among these groups.<sup>(65)</sup> The findings from this study are described herein and are categorised under; experiences of health service utilisation; sources of support and homecare; barriers to accessing homecare; and preferences for homecare.

#### **2.10.5.1 Experiences of health service utilisation**

Overall, study participants reported positive experiences with the health system and included effective communications and kindness as strong attributes among healthcare professionals. However, negative experiences reported related to discrimination accessing services enhanced by a "lack of awareness of entitlements" and a "lack of availability of affordable and accessible transport" to attend services. In addition, access to health services was hindered by not having a permanent address, absence of a postal service to deliver health appointments and communication difficulties, for example, low levels of health literacy and cultural differences.<sup>(65)</sup>

#### **2.10.5.2 Sources of support and homecare**

Sources of support and homecare included the important role that informal care played in these population groups. Informal care included personal care and domestic care and supporting access to formal healthcare, especially when literacy was an issue. Older homeless adults reported getting help mostly from homeless service volunteers and key workers which was often outside their working role. The help received was mainly with assisting with daily tasks, filling out forms, accessing and attending medical appointments. It was highlighted that in some cases the level of care was complex and too much for the carer and hence not sustainable. This subsequently resulted in a lack of consistent and comprehensive supports.<sup>(65)</sup>

#### **2.10.5.3 Barriers to accessing homecare**

Barriers to accessing homecare were divided into bureaucratic and structural barriers. The complexity of care needs and requirements for integrated care resulted in missed opportunities with care delivery. A study participant reported that the age and disability criteria for personal care schemes led to ambiguity and potential unmet needs across CHOs. For example, age groups 50-60 years may not be facilitated as they are not considered old. This is noteworthy considering the National Guidelines and Procedures for the Standardised Implementation of the Home Support Service (2018) refers to flexibility relating to access to home support for people aged less than 65 years if their assessed needs can be best met by Services for Older People.<sup>(29)</sup> Structural barriers include the residential settings such as mobile homes which may not be suitable to provide care in.<sup>(65)</sup>

#### **2.10.5.4 Preferences for homecare**

Preferences for homecare by study participants are described under four areas and are listed with a brief summary below:

- awareness and access - provision of accessible information and knowledge on home supports and home support services
- approach to delivery - home support workers and services need to be cognisant and sensitive to: the cultural needs of the older Traveller; possible low levels of literacy that may impact ability to advocate for one's own care needs and preferences; and potential for experienced disadvantage and trauma in one's life.
- range of services - services should include personal care, domestic care and companionship. Social interaction will address loneliness and isolation. In addition, services should be provided to help with developing house-keeping or self-care skills, if the person did not ever have opportunities to learn them and to support the transition through different housing types were recommended.
- homecare workers - homecare workers must be kind, patient and friendly. Building trust is imperative to establishing an effective relationship. The study recognises the contributions of national groups such as Primary Health Care Traveller Projects, homeless organisations and residential services, local authority workers, and HSE agencies and staff (such as public health nurses and social inclusion officers) in assisting the wellbeing of these groups.<sup>(65)</sup>

The briefing report concludes with 20 recommendations to uphold equity in homecare provision for older Traveller adults and older adults who have experienced homelessness. There is a focus on homecare reforms to consider the complex, diverse and sensitive needs of minority populations including recognition that the needs of these population groups extend beyond traditional homecare. Reference is made to the Professional Homecare Bill and embedding these groups in this legislation by publicly mandating a holistic person-centred approach to care and support that is underpinned by an understanding of shared and individual life experiences, and thus shifts the focus from a 'one-size fits all' perspective. In addition, the report suggests that homecare supports are not determined by a fixed chronological age threshold but take a flexible and early intervention approach.<sup>(65)</sup>

#### **2.10.6 An inquiry into the lived experience of COVID-19 in the homecare sector in Ireland, the experiences of homecare provider organisations (2020)**

This report, produced by Home and Community Care Ireland (HCCI), a national representative body for homecare providers in Ireland, discusses the impact of the COVID-19 pandemic on its members.<sup>(66)</sup> The main focus was to explore the challenges experienced during the first wave of the pandemic, approaches to address these challenges and the overall impact on the staff health and wellbeing. A questionnaire comprising 10 open-ended questions pertaining to management, service provision, relationships, health and wellbeing, and the future was emailed out to HCCI members. The emergent themes from responses included: challenges relating to recruitment and retention with workforce shortages; reduced and suspended services due to clients self-isolating, uncertainty, fear and worry relating to the pandemic; supply of personal protection equipment (PPE); communication issues between the national HSE office; HSE reporting process time-consuming; remote working bringing a new workflow, restructuring and redeployment.<sup>(66)</sup> Despite communication issues being identified as a challenge, providers commented on excellent collaborations with the HSE and forming an improved and strengthened relationship with the HSE. In addition, providers reported that helpful strategies during the pandemic were the HSE helpline, infection prevention and control training and the online learning and development platform on HSE LanD. The report found that the impact of COVID-19 on nursing homes has shifted a focus on homecare as a safer approach to providing care and concludes with key actions for consideration by the HSE, government and homecare provider organisations.<sup>(66)</sup> Key actions include the following:

- an integrated and centralised communication system
- standardised policy approach to model of care across CHOs
- a rapid review of homecare workforce
- interventions to promote staff wellbeing
- application of technology
- infection prevention and control measures regarding COVID-19.<sup>(66)</sup>

### **2.10.7 Report of the Policy Dialogue on the New Homecare Scheme, Centre for Economic and Social Research on Dementia (2020)**

The Centre for Economic and Social Research on Dementia (CESRD) at the National University of Ireland (NUI) Galway undertook this policy dialogue in which four topics were discussed: the homecare continuum; care planning and organisation of care delivery; regulating for quality; and funding.<sup>(67)</sup> These four areas were key areas emerging from a public consultation on homecare conducted by the Department of Health. Participants who took part in the policy dialogue on these four topics were people using services, advocacy groups, academics, service providers and government departments. The aim of the dialogue was to explore

participant's views through open discussion and gain insight into a consensus on each. Findings included:

1. There is a lack of clarity of the purpose of homecare.
2. Homecare is currently focused on enabling discharge from acute hospital and should have a wider focus on health production, maintaining health and preventing health problems.
3. A need to move beyond a 'one size fits all' approach to homecare and promote individualised or personalised care.
4. The needs of carers should be recognised more in homecare delivery.
5. An approach to enhancing current home support is to increase home support hours.
6. A single assessment tool was welcomed.
7. Engage directly with the person who requires homecare.
8. Regulation of homecare and homecare workers, with a focus on the service and not the setting is needed. The importance of outcome measurements and valuing staff was highlighted.<sup>(67)</sup>

Researchers reported a preference from participants for the term 'home support' over 'homecare' as the term 'support' assumes the existence of strengths and abilities in the person using the service who needs help and assistance, which may also include the provision of care. Moreover, it suggests doing something with a person rather than doing it for the person.<sup>(67)</sup>

### **2.10.8 COVID-19 Nursing Homes Expert Panel Examination of Measures to 2021 - Report to the Minister for Health**

In response to the COVID-19 pandemic, the Irish National Public Health Emergency Team (NPHET) recommended the establishment of an Expert Panel on Nursing Homes in May 2020.<sup>(62)</sup> The Expert Panel used an evidence-informed and consultative approach to complete its work, which included a review and analysis of available epidemiological data; a review of measures to protect older people in long-term residential care settings; consultation and engagement with stakeholders; and site visits. The consultation process received input from nursing homes, representatives and professional organisations, residents, staff, and family members. The following key themes were consistently identified across the stakeholders' engagement: timeliness of response, challenges presented by managing a new disease, implications for any future model of care, interdisciplinary cooperation, the role of GPs in providing care and leadership, staffing in nursing homes, community and regional response, and future protective measures.

In August 2020, the Expert Panel published a report summarising complex issues surrounding the management of COVID-19 among nursing homes residents. It also included evidence-based recommendations aimed to safeguard the residents in nursing homes and reflect the systematic reform that is needed in the way nursing home care and older persons care is delivered in Ireland.<sup>(62)</sup>

In relation to homecare and support, the report highlighted that “there is increasing evidence to show that highly dependent persons can live safely and more happily in domestic settings, provided their required homecare supports are in place”. It stated that post COVID-19 recovery plans are required, to include public health and speedy access to homecare packages. It reported that “patients should not be admitted directly to long-term residential care without being given the choice and a care needs assessment and appropriate opportunity to stay in their own home, following appropriate access to rehabilitation or reablement opportunity and access to a homecare package that meets their needs.”<sup>(62)</sup> Accordingly, the report recommended that “Access to home support should be expanded and prioritised”.

The report also recommended the development of an integrated IT system for older persons’ services, to support the effective sharing of information across residential settings, home support, and day care, and including needs assessment and care planning. The system would support the provision, management, delivery and reporting of services. It would also support planning alternative service provision and planned capacity development in the event of evolving public health measures.

### **2.10.9 Joint Committee on Health Report on the Provision of Homecare Services (2019)**

The *Joint Committee on Health Report on the Provision of Homecare Services* examined the provision of homecare services in Ireland.<sup>(68)</sup> The Joint Oireachtas committee also met with representatives from various voluntary groups who provide homecare services including Age Action Ireland, Care Alliance Ireland and Home and Community Care Ireland. The report describes the landscape of homecare across Ireland and highlights the many challenges encountered in the sector and acknowledges the need for change.<sup>(68)</sup> It is recognised that there are increasing demands on the sector resulting in long waiting lists and hence, the HSE has become reliant on voluntary organisations to provide the majority of homecare services.<sup>(68)</sup> In addition, the voluntary organisations are faced with their own challenges with staff retention and recruitment, funding and communications with the HSE. The Committee was informed by scenarios relating to time spent providing homecare such as 15-30 minute homecare visits, and this was deemed inadequate

in providing quality care. These scenarios are supported by a table showing a reduction in average annual number of publicly-financed homecare hours for persons aged 65 years and over from 2012 to 2015 in some counties in Ireland. An example of this table is displayed in Table 2.5. The report makes reference to the *Sláintecare* report and its focus on integrated, primary and community care and reaching targets set by the *Sláintecare* programme.<sup>(68)</sup>

**Table 2.5: Average annual number of publicly-financed homecare hours per person aged 65+ by County, 2012-2015**

Geographic area	2012	2013	2014	2015	% change 2012-2015
Carlow	22.3	22.6	22.7	21.1	-5.29
Cavan	29.9	28.5	28.2	27.9	-6.48
Clare	16.7	17.0	16.9	19.5	17.00
Cork	29.5	27.0	28.3	25.3	-14.25
Donegal	30.0	26.2	29.9	30.1	0.54
Dublin North	22.6	27.2	29.6	32.5	43.81
Dublin South	15.9	16.0	15.8	16.6	3.79
Galway	25.3	24.4	24.8	24.6	-2.81
Kerry	31.4	29.6	31.1	30.0	-4.55
Kildare	19.2	18.6	17.1	18.5	-3.61
Kilkenny	21.2	20.0	20.3	18.8	-11.18

**Source:** Joint Committee on Health (2019). Report on the Provision of Homecare Services.<sup>(68)</sup>

Following this review, the Joint Committee on Health made the following recommendations:

1. The enactment of legislation underpinning the provision of homecare. This legislation must set out to provide a definition of homecare, the eligibility for homecare and the statutory obligations on the HSE to provide homecare.
2. Homecare services are regulated by HIQA or another independent body which should be responsible for regulating the standard of care provided by professional carers, the commissioning of services by the HSE to voluntary organisations and the provision of homecare services.
3. Family carers are provided with adequate support to encourage informal homecare support.
4. Formal care should be delivered by appropriate qualified service providers who should be given adequate support to ensure:
  - a standardised quality of care
  - equity of working conditions for carers, with regular consistent working hours, travel expenses and contracts
  - carers have options of career pathways.

5. An examination of the role of voluntary organisations in publicly-funded health and social care services be implemented to improve and drive the relationship between the HSE and voluntary homecare service providers.
6. HSE records and publishes details of the number of people on waiting lists for homecare and are included in key metric data.
7. Single Assessment Tool (SAT) is fully implemented nationally.
8. HSE engage in open and transparent communications with the voluntary sector in relation to planning and funding.
9. An analysis be undertaken by the Department of Health and the Department of Public Expenditure and Reform, to examine the financial challenges of the voluntary sectors and their ability to provide homecare services.<sup>(68)</sup>

#### **2.10.10 Improving Homecare Services in Ireland: An Overview of the Findings of the Department of Health's Public Consultation (2018)**

This public consultation was conducted between July and October 2017 by the Department of Health to help develop plans for a new statutory scheme for homecare services. The consultation set out to understand what people thought about current homecare services, including what was working well and what needs to be improved, as well as the public's views on what the future scheme should look like.<sup>(69)</sup> A report, produced and published by the Institute of Public Health in 2018 provides an analysis of the responses to this public consultation. The total number of responses was 2,629, of which 104 were authorised responses from named organisations. 92.8% of respondents indicated that national quality standards should apply to all (public, private and not-for-profit) providers of homecare and 92.1% agreed that that formal homecare workers should have to complete a minimum level of training set by the government and be supported in continuous professional development. 92.3% of respondents agreed that there should be standardisation in needs assessment. In addition, emphasis was placed on the need for a person-centred care model that has impact across health and social care delivery, service providers, health and social care professionals and people using services.<sup>(69)</sup> The key themes that emerged from the responses included:

- the development of a statutory homecare system
- the need for a clear definition of homecare services
- a person-centred model of homecare
- the roll-out of the Single Assessment Tool (SAT)
- a more integrated approach to service delivery
- better integrating the community and voluntary sector
- housing options for older people
- skills and training in the homecare sector

- the regulation of homecare
- funding homecare.<sup>(69)</sup>

### **2.10.11 Improving homecare services in Ireland, Home and Community Care Ireland (HCCI) (2018)**

*Improving homecare services in Ireland* is a set of recommendations submitted by Home and Community Care Ireland (HCCI) in response to an overview of the homecare sector in Ireland that was published by the Oireachtas Library.<sup>(42)</sup> Recommendations in this document include:

1. The introduction of a statutory homecare scheme similar to that of legislation set for long term care through the Nursing Home Support Schemes.
2. Have one budget, for example combine budgets for Nursing Homecare and Homecare. Means testing and tax relief will ensure more individuals fund and avail of homecare services.
3. To offer a monetary contribution towards homecare needs, so to allow an individual and their family the choice of what provider they want to receive homecare from, that being public, private or a voluntary body.
4. An independent authority, for example, HIQA implements regulation and standards to drive higher quality and safe care.
5. Government continues to support Homecare Allowance for family and friends who are informal carers, including employment, income and social care supports.
6. Improvement of payment to care workers and include travel costs.
7. Introduction of the Single Assessment Tool (SAT) to decipher if homecare, assisted living, or nursing homecare is required. Utilise technology, for example digital health solutions.<sup>(42)</sup>

### **2.10.12 HSE and Genio Dementia Programme 2012-2018**

The *HSE and Genio Dementia Programme 2012-2018* began following government policies seeking to transform models of care for people living with dementia. The programme was made up of a number of projects that provided learning from best evidence and existing community services and practices.<sup>(21)</sup> The overall aim was to transform these services to support people with dementia to live at home for as long as possible using a personalised and cost-effective approach.<sup>(21)</sup> Two studies were undertaken as part of the programme and place a focus on home support services. They will be discussed under section 2.10.10 and 2.10.11. They are *Supporting Older People with Complex Needs at Home: Report 1: Evaluation of the HSE*

*Intensive Homecare Package Initiative and Supporting Older People with Complex Needs at Home: Report 2: What Works for People with Dementia?*

**2.10.13 Supporting Older People with Complex Needs at Home: Report 1: Evaluation of the HSE Intensive Homecare Package Initiative 2018**

The *Supporting Older People with Complex Needs at Home: Report 1: Evaluation of the HSE Intensive Homecare Package Initiative* report was commissioned as part of the National Dementia Strategy implementation programme, with an aim to evaluate the effectiveness and the feasibility of providing homecare to an older person with complex care needs pertaining to the intensive homecare package (IHCP).<sup>(15)</sup> This was a mixed-methods and multi-participant design study conducted across Ireland. The findings from this study recognised that the IHCP is available to a wide range of people with a wide range of complex needs. The study identified that the IHCP is feasible and is effective at facilitating people to stay at home.<sup>(15)</sup> However, some barriers to implementation were identified, including communication among stakeholders, availability of home support workers, and lack of reliable data.<sup>(15)</sup> This report highlighted the inconsistencies across service provision in Ireland but, in doing so, acknowledged that it is a 'wider HSE issue' and mainly attributed to environmental variations such as transport, cultural issues and geography and hence, the standardisation of the process may not be possible.<sup>(15)</sup> The report recommends standardising the outputs and outcomes of the service as a possible alternative approach. In addition, emphasis is placed on the importance of informal carers and advocates that their role cannot be underestimated, as some carers may be providing up to 100 hours of supervision and care per week and this is not sustainable to do alone.<sup>(15)</sup> Finally, the report makes some recommendations based on their findings as follows:

- IHCPs should be part of the 'complete continuum of care', with the provision of home support being assessed and planned jointly with the person and the family
- The content of IHCPs should best meet the needs of the person and family carer and should not be limited to homecare hours
- Families should be treated as key care partners and form part of the assessment, design and reviewing of care packages through shared decision-making processes
- Flexible working arrangements and carer leave schemes should be considered to provide practical support to family carers
- There is no certainty that family commitment will remain unchanged into the future.

- The value of homecare as an 'early intervention' approach to prevent premature loss of abilities and mobility should be recognised
- A workforce plan which addresses the training needs, pay and working conditions of homecare workers is needed
- If home support services are to act as an alternative to long term care for older people or to support timely discharge from acute care services and the avoidance of inappropriate admissions, increased funding should be allocated to homecare and support services, as recommended by the Health Service Capacity Review (2016) and Sláintecare Report (2017)
- Privately funded care hours is increasingly evident
- Routine collection of data and quality indicators on homecare relating to people with dementia and all older people is required to monitor the types of homecare provided, quality of homecare delivery, and outcomes of homecare delivery for individuals.<sup>(15)</sup>

#### **2.10.14 Supporting Older People with Complex Needs at Home: Report 2: What Works for People with Dementia? 2018**

The *Supporting Older People with Complex Needs at Home: Report 2: What Works for People with Dementia?* report was commissioned as part of the National Dementia Strategy implementation programme, with an aim to design, manage and undertake a study of dementia-specific intensive homecare packages to evaluate their effectiveness and how well they are working. This report informs that there are approximately 55,000 people with dementia in Ireland, with the majority being women. The level of severity of dementia among these people is unknown.<sup>(16)</sup> A description is given on the care needs for a person with dementia and how these needs can differ from that of the general older population groups. For example, care demands can be associated with the behavioural and psychological symptoms of dementia and this can impact on carers. The study involved an analysis of IHCP for over 500 people, 59% of the study population had dementia and involved interviews with people with dementia and or their family carers.<sup>(16)</sup> Findings concluded that caring for a loved one at home was very important and a preference for family carers as opposed to placement in a nursing home. Findings indicated cost savings with enabling a person to stay at home and providing them with an IHCP as this will reduce the likelihood of admission to residential care settings.<sup>(16)</sup> The report lists many recommendations with similarities to *Supporting Older People with Complex Needs at Home: Report 1: Evaluation of the HSE Intensive Homecare Package Initiative* including the important role of the family carer. Other recommendations include the following:

- The rollout of carer's needs assessment as part of the SAT will promote involvement of family, but training will be needed to support shared decision-making and identification of priority needs and goals for the person and carer
- Education and training on the personalised care approach is required for all homecare workers and health and social care professionals, especially PHNs, as they often take the lead with care needs assessment
- Continuity of care and ongoing communication with the person and carer should be incorporated into procurement processes to improve the experience of care for older people, people with dementia and their families
- The use of technology, such as applications and other software to share real-time data, could be considered to improve communication for the person and family carer and to streamline the provision and scheduling of care.<sup>(16)</sup>

### **2.10.15 Developing and Implementing Dementia Policy in Ireland (2017)**

*Developing and Implementing Dementia Policy in Ireland (2017)* is a report that reflects on various aspects of care for people with dementia, both in Ireland and internationally, with an aim of informing further developments in dementia policy. The policy provides an analysis on the prevalence of dementia in Ireland, with an expected number of 115,426 people living with dementia in Ireland by 2036. Diversity exists among people with dementia and hence the policy calls for more novel approaches to understanding dementia and its experiences. This also highlights the importance of individualised and personalised approaches to supporting people with dementia.<sup>(70)</sup>

The analysis estimates that there are approximately 60,000 informal carers providing care to people with dementia living in communities in Ireland. The care delivered by informal carers can range from direct personal or practical care provision, organising care delivered by others, and supporting and assisting decision-making. It is important that both formal and informal care work in equal partnership. Recognition needs to be given to informal care givers in that they may be more cognisant of what is acceptable and not acceptable to the person with dementia.<sup>(70)</sup>

Dementia has evolved from being medically managed to a social management approach that aims to preserve and promote personhood in the provision of services and supports that encourage engagement and empowerment. An emerging agreement is the need for "the development of a bio-psycho-social model of care that reflects the medical, social, behavioural, psychological and emotional needs of the person with dementia and their caregivers."<sup>(70)</sup> Recommendations made in the

policy is that future policy should promote recognition of the human rights of the person and their family. The report explains that if human rights principles and the principles of citizenship and personhood are to be introduced into Irish services, there is a need to provide clear guidelines on what these principles mean to the person, family members, health service professionals, frontline staff and care regulators. Recent projects such as the HSE and Genio cooperation and the Intensive Homecare Package have led to changes in homecare services and care delivery for people with dementia. The policy offers ways in which resources can be allocated to personalise the care given and includes the importance of education in the change process. This includes public information campaigns that can shift attitudes, such as those that assume dementia strips a person of their autonomy. The report highlights the importance of embedding a culture of person-centred care in work practices that can be enhanced by valuing and nurturing staff who are providing person-centred care. The report recognises that homecare provision for people with dementia in Ireland is weak and people continue to have unmet needs. The provision of care needs to be tailored to the individual needs and will require funding, expansion of services, coordination, integration and regulation. Better working conditions such as pay rises, training and more valued sustainable career pathways will attract people to the homecare profession. Final recommendations include building on the National Dementia Strategy by developing a second strategy.<sup>(70)</sup>

#### **2.10.16 A National Model of Care for Paediatric Healthcare Services in Ireland Chapter 18: Community Services for Children with Ongoing Health Needs (2016)**

*A National Model of Care for Paediatric Healthcare Services in Ireland* was developed by the HSE in 2016 as part of the HSE National Clinical Programme for Paediatrics and Neonatology. This model was developed from consultations with healthcare professionals, parents and parents groups, analysis of activities of all sectors of healthcare pertaining to paediatrics including primary, secondary and tertiary care services and international best practice. The model comprises of 45 chapters including governance, integrated care and subspecialties such as paediatric palliative care, paediatric neurosurgery and paediatric gastroenterology.<sup>(71)</sup> Chapter 18 discusses community services for children and highlights the need for a nationwide standardised model of care that specifically addresses primary care paediatric services. The model places an emphasis on a multi-agency approach to paediatric care in the community and begins with the need to provide paediatric care as close to the home as possible. This can be achieved using integrated services supported by appropriately skilled staff. In addition, appropriate levels of respite and home support should form part of national primary care and social care service plans.<sup>(71)</sup>

Subsequently, this will promote equity of access for children and their families. The model recognises the need for individual services and professionals to work together in a consistent, coordinated and integrated approach that meets the needs of the child and their families. The model of care for services for children in the community should be underpinned by the following key principles:

- Child-centred and family-centred care that “places the child and the family at the centre of everything the service does.”
- Ease of access including a national access criteria and adequate resources.
- Early detection and diagnosis encompassing a “robust child health surveillance and screening programme.”
- High-quality integrated care that is “safe, clinically effective, person-centred, and delivered in a timely, efficient and equitable manner.”<sup>(71)</sup>

Recommendations are made including national standards for communication between agencies providing care services to children, in order to place communication at the centre of an integrated service. In addition, the development of information and communications technology (ICT) systems for all community services that will also link in with ICT systems in acute hospitals will enhance communications between services. Primary Care Paediatric Network-level Services, Children’s Disability Network Teams, and Child and Adolescent Mental Health Services (CAMHS) should be established alongside a national competency framework for healthcare professionals caring for children in the community. National integrated care pathways and appropriate outcome-based key performance indicators should be used to measure the effectiveness of services and offer quality assurance.<sup>(71)</sup>

### **2.10.17 Access to Life: Personal Assistant Services in Ireland and Independent Living by People with Physical and Sensory Disabilities, Disability Federation of Ireland (2014)**

The report *Access to Life: Personal Assistant Services in Ireland and Independent Living by People with Physical and Sensory Disabilities* is based on research conducted to examine Ireland’s personal assistance (PA) service.<sup>(72)</sup> Personal assistance is a service available for people with significant physical and sensory disabilities and is mainly funded by the HSE. The overall objective is self-empowerment to overcome the disadvantages caused by physical and sensory impairments. A Leader is the person with a disability who is receiving the PA service. Thirty participants who use PA services were interviewed (one-to-one interviews) to explore their experiences of the service. The participants reported an understanding of the difference between care services and a PA service and while they felt they were a Leader, their scope to manage the service varied. Areas they felt were

important include power over PA recruitment, primary responsibility for PA training and having support if an issue occurred. The role of a PA demands flexibility and interpersonal skills and hence appropriate pay and conditions alongside health and safety regulations are required. A concern expressed among participants was sustaining the service, access to additional hours if their conditions worsened or if they wished to leave their home where their parents live. The final conclusion was that the original scope for a PA service, that being enablement, had been undermined to be just a care service. In addition, senior staff in eight PA service provider organisations, one senior HSE official, representatives from advocacy, education and research areas and six people from voluntary disability organisations were interviewed and provided insights into the evolution of PA services in Ireland and policy perspectives.<sup>(72)</sup> The report makes some recommendations as follows:

1. The Department of Health should develop a definition of a PA service ensuring it reflects the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).
2. PA services should be established on a statutory basis.
3. The Department of Health should commission an independent evaluation of the PA service.
4. Government should explore new ways of funding the service, similar to that of the Australian National Disability Insurance Scheme.
5. The HSE needs to engage with Leaders and the disability sector to clarify what a PA service is and what a PA service does. Facilitate the Leader becoming the employer and have pathways to direct payments.
6. The HSE's assessment process needs to include independent living activities named by the applicant.
7. Leaders should have choice about how they use the PA service. The focus is on the person achieving independence and not on the aspects of service provision.
8. HSE has a role in self-help and providing information on PA services.
9. Development of HSE or HIQA standards and regulations for the service should be co-developed with Leaders.<sup>(72)</sup>

#### **2.10.18 Quality and Standards in Human Services in Ireland: Homecare for Older People, National Economic and Social Council (2012)**

The report *Quality and Standards in Human Services in Ireland* examines standards in homecare in Ireland. It begins with a history of homecare in relation to home help

and homecare packages and the delivery of these services by the HSE, voluntary and private organisations.<sup>(73)</sup> The report also highlights that government committed to bring regulation of homecare providers into legislation following the Law Reform Commission report, 2011. The quality standards drafted by the HSE for tendered organisations to comply with are set out under five themes: responsive regulation (which is how implementation of quality standards is encouraged by a balance of sanctions and supports); involvement of the service user; monitoring and learning; devolution and accountability; and addressing costs while improving quality. The report highlights that only those organisations employed under the tendering process to deliver homecare packages are required to meet certain standards, which leaves other homecare services not required to meet the standards. This can lead to risk of harm in the area of homecare. The report provides definitions of homecare which is "care provided in the home to a person who needs assistance with activities of daily living over an extended period of time."<sup>(73)</sup> Subsequent chapters include descriptions of the HSE quality standards with concluding recommendations being service user involvement in all standards frameworks, having co-ordinated learning and legislative underpinning of the homecare sector. It is highlighted in this report that having mandatory standards motivates their implementation and if tendering organisations are in competition with each other to gain business from the HSE, they are less likely to collaborate and share knowledge.<sup>(73)</sup>

## 2.11 Summary

The primary goal of homecare and support services in Ireland is to facilitate people to live in their own homes as independently as possible, for as long as possible, if they wish to do so. There is currently no legislation or statutory regulations underpinning the homecare and support sector in Ireland. There have been long-standing calls for the introduction of legislation to support and safeguard people using homecare and support services in Ireland from successive governments, researchers and advocacy groups. In addition, the current homecare and support sector is largely reliant on informal carers providing care to people to live in their own homes.<sup>(3)</sup>

The main findings from this review of services in Ireland are summarised as follows:

### **Legislative context**

- There is currently no legislation or statutory regulations underpinning the homecare and support sector in Ireland. There is a need for regulatory reform to ensure delivery of care that meets the needs of the Irish population.

### **Drivers for improvement**

- The current homecare and support sector is largely reliant on informal carers providing care to people to live in their own homes.
- The Sláintecare (2017) report outlines recommendations related to social care expansion, including universal access to homecare.
- HIQA published a position paper on the regulation of homecare in 2021. In it HIQA advocated that homecare services need to be needs led, integrated, and inclusive of complex care. Age or disability status should not be a barrier or gatekeeper to access homecare and support services.
- Homecare and support services should support enablement and independence, ensuring the dignity and human rights of people are protected.
- Homecare and support services should be person centred, focused on quality and on the outcomes important to those receiving the service.

### **Models of care and integration**

- While homecare and support services are allocated based on need and availability of resources, rather than the individual's ability to pay, there is high demand for services and waiting lists remain.
- National HSE guidelines and service specifications for tenders to provide home support services are already in place for older persons.
- Despite this, inconsistencies remain in home support services for adults (including older persons and people with disabilities), including funding arrangements, assessment of need, eligibility criteria and allocation of resources.
- Variation is also evident in homecare and support services for children with complex needs in our communities.
- Information and Communications Technology (ICT) has a critical role to play in ensuring that information to drive quality and safety in health and social care settings is available when and where it is required.

### **Workforce**

- Home support in Ireland is provided by staff employed by the HSE, voluntary organisations and for-profit organisations.
- There is limited information about the total number of carers employed in Ireland.
- It is widely acknowledged that the sector is challenged by staff recruitment and retention.

#### **2.11.1 Access to care, assessment of need and integration**

Publicly-funded homecare and support in Ireland is available free of charge, is not means tested and no contributions are required by the person using the service. However, as homecare and support services are allocated based on need and availability of resources rather than ability to pay, the provision of homecare and

support by the state is subject to available resources and hence waiting lists are evident.

Publicly-funded home support services are funded by the State through budgets allocated annually to the Health Service Executive (HSE). These home support services are then either provided by staff directly employed by the HSE or by voluntary (not-for-profit) or private (for-profit) providers who are funded by the HSE to provide services through a tendering process. Individuals may also purchase home support services directly from private providers operating independently in the open market. The HSE has no oversight of these privately-funded services.

Access to publicly-funded homecare and support in Ireland is based on assessed need. An assessment of need is conducted to explore the needs of the person and appropriate supports required. National guidelines and service specifications for tenders to provide home support services are already in place for older persons. Notwithstanding this, the literature highlights inconsistencies which remain in home support services for adults (including older persons and people with disabilities), including funding arrangements, assessment of need, eligibility criteria and allocation of resources.

Inconsistencies are also evident in homecare and support services for children with complex needs in our communities. Reform of homecare and support services in Ireland presents an opportunity to establish a framework for best practice in providing person-centred homecare and support, without age restrictions, with a focus on achieving the best outcomes for all people using these services.

### **2.11.2 Workforce**

Home support in Ireland is provided by staff employed by the HSE, voluntary organisations and for-profit organisations. Currently, outside of the HSE, little is known about home support workers in Ireland, including the total number of carers employed.<sup>(4)</sup> Home support workers in Ireland are not required to register with a professional health and social care registration body. It is widely acknowledged that the sector is challenged by staff recruitment and retention.<sup>(4)</sup> There have been calls to the Irish government for a comprehensive workforce review in social care in order to address the current recruitment and retention challenges and the increase in demand for homecare and support.

### **2.11.3 Information and Communications Technology (ICT)**

Information and Communications Technology (ICT) has a critical role to play in ensuring that information to drive quality and safety in health and social care settings is available when and where it is required. However, a review by HIQA of

ICT enablement of older persons services in Ireland<sup>(5)</sup> shows that the current ICT infrastructure in Ireland's health and social care sector is highly fragmented, with major gaps and silos of information which prevents the safe, effective transfer of information. This review demonstrates a clear and pressing need to develop a coherent and integrated approach to health information, based on standards and international best practice.

#### **2.11.4 Drivers for improvement**

It is evident from the array of published literature and reports that Ireland is deeply committed to improving homecare and support services. Research has been conducted by subject matter experts from government departments, State bodies, Irish universities, advocacy groups and public, private and voluntary homecare and support providers, all of whom share common recommendations that Ireland needs legislation to underpin the provision of quality homecare and support. The ten-year strategic framework set out in Sláintecare aims to "make it possible for people to stay healthy in their homes and communities for as long as possible, receiving the Right care, in the Right place, at the Right time, delivered by the Right team"<sup>(6)</sup> The Sláintecare (2017) report outlines Sláintecare's recommendations related to social care expansion, including universal access to homecare.<sup>(7)</sup>

#### **2.11.5 Proposals for a regulatory framework**

HIQA published a report on *The Need for Regulatory Reform* in 2021<sup>(8)</sup> that summarises HIQA's experience of regulating social care services and outlines why change is needed to make regulation fit-for-purpose into the future. The report outlines the challenges currently faced by the homecare sector; for example, the lack of statutory entitlement to formal homecare and the current variation in access to homecare services. Emphasis is placed on the need for investment in regulatory reform to ensure the capacity and capability to deliver care that meets the needs of the Irish population.<sup>(8)</sup> The report also states that the provision of good quality homecare should be a key component of any future social care system. HIQA subsequently published a report on *Regulation of Homecare: A Position Paper* that sets out HIQA's position on the future of regulating homecare services in Ireland.<sup>(9)</sup> This report was published in conjunction with a review of the current homecare landscape both nationally and internationally entitled *Regulation of Homecare: Research Report*.<sup>(1)</sup> Based on the evidence, HIQA recommended priority areas for the regulation of homecare services in Ireland in the position paper as follows:

- be inclusive to all who are in receipt of formal homecare
- improve the performance and quality of homecare
- provide assurance to people receiving homecare and the public that

- minimally acceptable standards are achieved
- provide accountability on both performance and value for money.<sup>(9)</sup>

HIQA has strongly advocated for a complete review and, where necessary, an overhaul of the homecare sector. HIQA also strongly advocated that homecare services need to be integrated and needs led, removal of any barrier to access (such as age), and services that support enablement and independence to be accounted for, ensuring the human rights of people in receipt of homecare are protected. HIQA highlighted that while it is up to the Government to decide if more complex aspects of care will be included in the regulation of homecare, it should consider that health and social care services intersect frequently and are often integrated, and there is a strong argument that this will increase over the coming years with the move to more care in the community at the heart of the Sláintecare ethos.<sup>(9)</sup>

A statutory entitlement to homecare and support services would help to address the current inequities in service delivery. It is envisaged that the implementation of national standards underpinned by legislation and regulations will also reduce variation in practice and promote quality person-centred care.

## **International review**



## **3. International Review**

### **3.1 Structure of the International review**

In order to inform the development of the standards an international review of homecare and support services in seven countries was conducted. These seven countries were selected following a desktop scoping review conducted by the Standards Development Team. As part of this scoping review, topic briefs were prepared for 24 countries: Scotland, Northern Ireland, Wales, England, New Zealand, Australia, Canada, United States, Netherlands, Denmark, Sweden, Finland, Germany, Greece, Spain, Portugal, Norway, Italy, Austria, France, Czech Republic, Cyprus, Croatia, and Belgium. Criteria for inclusion in the international review included applicability to the Irish context (for example, similarities in population and economic factors, structure of health and social care system), and English language or official translations available. Jurisdictions were not selected for the international review if homecare and support services were not regulated in legislation, if material was not available in English, or if there were no national standards.

Seven countries met this inclusion criteria, and these were selected for detailed review, including a desktop review and interviews with relevant international teams from Ministries of Health, standards development teams and health and social care regulators. The jurisdictions selected for in-depth review were:

- Scotland
- England
- Northern Ireland
- Wales
- The Netherlands
- New Zealand
- Australia.

The international review provides an overview of how homecare and support is structured in seven other jurisdictions internationally. The review examines key areas in relation to each of these jurisdictions, including relevant legislation, the model of service, standards and policies, the findings from reviews of services, and any lessons for Ireland.

### **3.2 Introduction**

Ireland is not alone in both benefitting from and being challenged by an ageing population. Healthcare and social policy developments in the second half of the 20th and early 21st century have resulted in a population that is experiencing increasing life expectancy and significant improvements in health and wellbeing. Citizens are

also much more effective in asserting their right to manage and control how and where any necessary care and support they require should be delivered.

As more people choose to receive care and support in their own homes, and as scientific and technological advances mean that increasingly complex care can be delivered in a domestic setting, there is an urgent need to provide assurances that high-quality care and support at home is delivered safely and efficiently. We need to build services today that will be suitable for our population tomorrow and into the future.

Other jurisdictions are addressing this imperative in ways that reflect their unique legislative and policy context, but which nevertheless offer significant learning for Ireland. All of the countries reviewed are exploring how to move from a regulatory environment that focuses primarily on organisational processes, to one that focuses instead on user-led outcomes, placing the service-user at the centre of all aspects of homecare services.

### **3.3 Scotland**

#### **3.3.1 Overview of home support services**

In Scotland, home support services, or care at home, are available without charge to all adults who have been assessed by the local authority as eligible for these services.

Similar to Ireland, the provision of home support has become increasingly important in recent years as Scotland's population is ageing, with the number of people aged 75 and over set to increase by 85% by 2039.<sup>(74)</sup> Scottish policy and strategy for older people is guided by the aim of older people in Scotland being valued and empowered to live independently, whereby their voices are heard, and they are supported to enjoy full and positive lives in their own home or in a homely setting.<sup>(75)</sup>

This section will examine the landscape of formal home support services in Scotland under the following headings:

- Structure and governance
- Scope and definitions of home support
- Eligibility and assessment of need
- Funding of home support
- Workforce
- Relevant legislation
- Regulation.

#### **3.3.2 Structure and Governance**

This section outlines the structure of formal home support services in Scotland, and how these services are delivered, supported, and governed.

The government in Scotland is structured into a number of directorates. Directorates and their related public bodies are responsible for putting government policy into practice. The Community Health and Social Care Directorate focuses on the health and care outcomes for people receiving care at home, ensuring that high quality care and support is provided to those who need it most, as close to home as possible. Their role is to provide policy advice to Ministers, implement health and social care integration, and support health and social care partnerships with practical support and guidance.<sup>(76)</sup>

The Community Health and Social Care Directorate also allocates resources and sets the strategic direction for NHS Scotland.<sup>(76)</sup> Together with the Housing Directorate, the Community Health and Social Care Directorate also supports the provision of

housing adaptations for people who need them, in order to maximise their potential for living independently at home.<sup>(74)</sup>

The National Health Service (NHS) Scotland is responsible for delivering or commissioning the provision of health and social care, including care at home. NHS Scotland currently employs approximately 140,000 staff across 14 regional NHS Boards, which are each responsible for the protection and the improvement of their population's health and for the delivery of frontline healthcare services. There are also seven Special NHS Boards and one public health body who support the regional NHS Boards by providing a range of specialist and national services. Each NHS Board is accountable to Scottish Ministers, supported by the Scottish Government Health and Social Care Directorates.<sup>(77)</sup> Where an NHS Trust delivers care at home (but not as part of part of continuing hospital care) then the Trust is registered as the provider of the care service.<sup>(78)</sup>

The Care Inspectorate is an independent regulatory body that inspects and monitors health and social care services in Scotland.<sup>(79)</sup> All services providing care at home must be registered with the Care Inspectorate. In Scotland there are currently 800 services registered to provide care at home. The majority of registered providers (51%) are from the voluntary sector, with the private sector providing 34% of registered home support services and Local Authorities and NHS Boards providing 15% of services.<sup>(78)</sup> The private sector is the biggest provider (49%) of stand-alone home support. Home support that has been funded by the Local Authorities is often delivered by a provider in the voluntary and or independent sector, with 37% of local authority-funded home support being provided by the voluntary and or independent sector in 2015.<sup>(78)</sup>

The Scottish Social Services Council (SSSC) regulates the social care workforce in Scotland by requiring all social service workers, including home support staff, to be registered with them. The SSSC supports the continuous learning and professional development of staff, publishes national codes of practice, and may revoke an individual's registration status if acceptable standards in conduct and practice are not upheld.<sup>(80)</sup>

### **3.3.3 Scope**

This section will describe the scope of home support services in Scotland, what tasks are included in each type of home support that is available, and how home support services are defined and distinguished from other forms of care.

People who are eligible for care at home services in Scotland include older persons (people over 65), children and young adults with disabilities, adults with learning or physical disabilities, adults dependent on alcohol or illegal substances and persons

with HIV or AIDS.<sup>(81)</sup> People being discharged from hospital may also be eligible for home support for up to 28 days following discharge. This eligibility is subject to a standardised needs assessment, and is means tested.<sup>(82)</sup>

Care at home in Scotland includes personal care and personal support. Nursing care may also be provided, however this is often dependent on local NHS partnerships. The definitions of the different types of care at home in Scotland are:

- **Personal care** means care related to the day-to-day physical tasks and needs of the person being cared for, like washing and eating.
- **Nursing care** means medical help, such as help with medications, changing dressings or catheters, and rehabilitation following a hospital stay.
- **Personal support** means counselling, or other help, provided as part of a planned programme of care.

According to the Scottish Government website <sup>(83)</sup>, you can receive the following types of personal care at home:

- cleaning, heavy housework and looking after your garden
- dressing and washing
- getting your shopping
- 'meals on wheels' or frozen meals delivery
- someone picking up your pension or any medicines you need
- sorting out bills
- laundry – this includes washing and ironing in your home
- equipment for your home, like special chairs or shower rails, to make living at home easier
- setting up a mobile phone for simple health checks, such as taking your blood pressure – this is known as 'telehealthcare'.<sup>(83)</sup>
- help with day-to-day physical tasks and needs of the person cared for, including helping them to remember to do things such as eating and washing.

The scope of home support services are defined in legislation, through The Regulation of Care (Scotland) Act 2001 and the Community Care and Health (Scotland) Act 2002. These pieces of legislation and their role in regulating Scottish home support will be discussed in more detail in section 3.3.7.

Home support services in Scotland includes services provided to people in their own homes or in supported accommodation, sheltered housing or elsewhere. It also includes those services traditionally referred to as "day care" whether they are provided in the home, in a care setting or elsewhere. It covers services provided or purchased by a local authority, services provided by health bodies which are not part of core NHS functions and other services independently provided which include an

element of personal care or personal support, except for services provided by an individual through direct arrangements with the recipient (for example an informal family carer, a paid personal assistant). It does not include field social work services such as those carried out by social workers in connection with their functions of assessment, care management, child protection and supervision of offenders. It also does not include domestic services which are not provided or purchased by a local authority or health body.<sup>(84)</sup>

The Community Care and Health (Scotland) Act 2002 sets out a list of personal care tasks that may not be charged for by a local authority. For example, this can be support with:

- personal hygiene
- at mealtimes
- immobility problems
- medication and
- general wellbeing.

Personal care and personal support are the types of social care not charged for by a local authority, as per this Act. This includes help with washing and eating. This Act clarifies that “nursing care” is distinct from personal care or personal support. Nursing care is care that involves the knowledge or skills of a qualified nurse and includes activities such as administering injections and managing pressure sores.<sup>(85)</sup>

The introduction of the Reshaping Care for Older People programme and the Change Fund initiative by the Scottish Government has aimed to commission more alternative services, such as preventative services.<sup>(86)</sup> An example of this is the collaboration of Local Authorities and NHS Boards in order to provide special short-term home healthcare to care recipients to prevent them from being admitted or re-admitted to hospital and to provide them with the necessary skills and abilities to live an independent life at home, with as little support as possible.

Lastly, many people receiving care at home services in Scotland also use telecare or telehealthcare, either as standalone support or combined with care at home services. <sup>(78, 87)</sup>. Telecare arrangements are varied. Some operate alone, some are integrated within an existing care at home service and some only operate a call centre where the alarm response is provided by another care agency or the person’s family or friends.<sup>(78, 87)</sup>

### 3.3.4 Eligibility and assessment of need

This section describes how a person's needs are assessed in Scotland in order to determine their individual care and support requirements, and how these assessments are standardised across a diverse population, with equally diverse needs.

If a person is in need of free care at home, an assessment of need will be arranged by their local authority and carried out by a registered care professional or healthcare worker, depending on workforce availability in the area. In some circumstances, for example following a hospital stay, a care recipient may also require an assessment of their finances to determine whether and to what extent they are eligible for financial assistance.<sup>(88)</sup> The Local Authorities' assessment determines what personal care services are required for the person receiving care at home so as to maintain or maximise their well-being.

This assessment aims to determine:

- what the person's care needs are, and
- how these care needs can be met.

These needs assessments can be referred to by any of the following:

- care assessment
- care needs assessment
- community care assessment
- joint needs assessment
- shared assessment, or
- single shared assessment.

Care needs assessments are carried out with consideration of the national eligibility criteria for social care. The national eligibility criteria for social care were agreed by the Scottish Government and the Convention of Scottish Local Authorities (COSLA), and while originally developed for older people, the criteria were explicitly designed to apply consistently across all age groups.<sup>(82)</sup> The criteria were used to form the National Eligibility Framework, against which a person's care needs are assessed.

#### **National Eligibility Framework**

The National Eligibility Framework employs a four criterion approach, categorising risk as being critical, substantial, moderate or low.

- **Critical Risk:** Indicates that there are major risks to an individual's independent living or health and wellbeing and likely to call for the immediate or imminent provision of social care services.
- **Substantial Risk:** Indicates that there are significant risks to an individual's independence or health and wellbeing and likely to call for the immediate or imminent provision of social care services.
- **Moderate Risk:** Indicates that there are some risks to an individual's independence or health and wellbeing. These may call for the provision of some social care services managed and prioritised on an ongoing basis or they may simply be manageable over the foreseeable future without service provision, with appropriate arrangements for review.
- **Low Risk:** Indicates that there may be some quality of life issues, but low risks to an individual's independence or health and wellbeing, with very limited, if any, requirement for the provision of social care services. There may be some need for alternative support or advice and appropriate arrangements for review over the foreseeable future or longer term.

In these definitions, the risks do not refer only to an individual's current independence, health and wellbeing, but also to the risk that she or he may not be able to gain these outcomes without support.

As part of policy decisions made around the national eligibility for free care at home, care and support plans should be finalised and delivered within six weeks of receiving a needs assessment, particularly if these people were determined to be in significant need of these services.<sup>(89)</sup> A review of people's care needs is expected to take place at least every six months, or more often if a person requests it, or an aspect of care or need changes.<sup>(78)</sup>

The national eligibility criteria and eligibility framework for assessing people's care needs have been identified as being potentially subjective in their application.<sup>(90)</sup> It is recognised that the use of eligibility criteria as a means of managing demand for social care is imperfect and unless properly deployed can result in resources being narrowly focused on individuals with acute needs or on specific client groups. There is also evidence that inappropriate application of eligibility criteria can hinder the person-centred and outcome-focused assessment and support planning that is essential to deliver the principles of choice and self-directed support outlined in Scottish legislation.<sup>(89)</sup>

### 3.3.5 Funding and commissioning

This section describes how home support services in Scotland are funded and commissioned.

Care at home in Scotland is funded through national and local taxes. Some services can be organised by a Local Authority but are subject to a fee, or income cap, including housework, laundry, shopping, out-of-home services such as day-care centres, and the cost of supplying food or prepared meals.<sup>(91)</sup> Since 2019, personal care and nursing care is provided free to all people who need it, regardless of their financial situation, subject to needs assessments.<sup>(83)</sup>

The principle of choice and self-directed support is emphasised when deciding where home support funding should be used, as set out in legislation through the Social Care (Self-directed Support) (Scotland) Act 2013.<sup>(91)</sup> This means that local councils may tell the person requiring care and support how much money there is to spend on their care plan, and the person may choose how to spend it. Alternatively, if they prefer, the person receiving care and support can ask the council to direct these funds to services that they think are most appropriate, from information gathering during their assessment of need. If a person under 65 is unhappy with the amount they have to pay, they can ask for a review by speaking to their local council's social work department.<sup>(91)</sup>

The introduction of the Reshaping Care for Older People programme and the Change Fund initiative by the Scottish Government has aimed to commission more alternative services, such as preventative services.<sup>(86)</sup> An example of this is the collaboration of Local Authorities and NHS Boards in order to provide special short-term home healthcare to care recipients to prevent them from being admitted or re-admitted to hospital.

People living in Scotland can get information and advice about care services available to them from a telephone and website service called Care Information Scotland. Information provided includes the range of services available, how to access care and their rights, care standards, and explanations of funding and entitlements including free personal and nursing care and direct payments<sup>(92)</sup>

### **3.3.6 Workforce**

This section describes how home support service staff in Scotland are supported and regulated, and outlines the registration requirements that must be fulfilled before they can carry out care at home.

As of January 2020, all home support workers must be registered with the Scottish Social Services Council (SSSC) and complete a set amount of post-registration training and professional development hours per year, depending on their role.<sup>(80)</sup> The SSSC does not specify which qualifications are accepted for registration as a home support worker, however for a qualification or degree to be suitable it must:

- Incorporate assessment against occupational standards or is based on the assessment of work-based competence.
- be designed to match a particular function or range of functions within social services, or meets registration criteria set by a nationally recognised regulatory body.
- be subject to a recognised and regulated form of external verification or assessment.
- integrate observed, assessed practice and learning.
- be recognised within a national qualifications framework.
- recognise the importance of underpinning knowledge and a value base that is consistent with the Code of Practice for Social Service Workers.

The Care Inspectorate expects all care providers to have comprehensive safe recruitment policies in place, which should include background checks, references, and ensure that employees are registered under the Protecting Vulnerable Groups scheme. Home support workers must hold a relevant qualification or be working towards gaining one that relates to the work they do. Staff must also be trained in appropriate food preparation and food hygiene practice.<sup>(78)</sup>

Staff providing care at home are also expected to undertake person-centred assessments of needs and risks, and should be appropriately qualified and trained to do so. This skill is needed in order to establish a personalised care and support plan for each person. The plan should set out how their health and wellbeing needs will be met, outline the person's likes, dislikes, goals and aspirations, and should contain a planned schedule of upcoming visits.<sup>(78)</sup>

### **3.3.7 Legislation**

This section describes the regulatory framework for home support services in Scotland and outlines the relevant legislation, including Acts and regulations made under these Acts.

The entitlement of home support services for Scottish residents is outlined in legislation. This section examines the pieces of legislation that form the statutory framework for regulating home support services in Scotland.

According to Scottish Law, people who are assessed by their local authority as needing home support services are entitled to receive this without charge, regardless of age or socioeconomic status. Care at home is legislated for in three major pieces of overarching legislation. These are:

- The Regulation of Care (Scotland) Act 2001<sup>(93)</sup>
- The Community Care and Health (Scotland) Act 2002<sup>(85)</sup>

- The Carers (Scotland) Act 2016.<sup>(94)</sup>

Furthermore, there are three pieces of legislation intended to protect, safeguard and empower people receiving social care and support. These are:

- Adults with Incapacity (Scotland) Act 2000<sup>(95)</sup>
- Adult Support and Protection (Scotland) Act 2007<sup>(96)</sup>
- The Social Care (Self-directed Support) (Scotland) Act 2013.<sup>(91)</sup>

Additionally, local authorities and organisations providing home support are under the remit of the following four legislative Acts, which establish health and social care sector reforms and give powers to the relevant bodies for inspection and registration of organisations or individuals involved in the delivery of home support. These are:

- Social Work (Scotland) Act 1968
- NHS and Community Care Act 1990
- Public Services Reform (Scotland) Act 2010
- The Public Bodies (Joint Working) (Scotland) Act 2014.

This section outlines in detail the key pieces of legislation involved in the regulation of home support services in Scotland, and the home support entitlement for Scottish residents.

### **3.3.7.1 The Regulation of Care (Scotland) Act 2001**

The Regulation of Care (Scotland) Act 2001 established regulatory mechanisms and a legal framework for the care sector, including home support. The main aim of the Regulation of Care (Scotland) Act 2001 was to improve the quality of social care services. The act reformed the regulatory system for home support services in Scotland and replaced a number of preceding pieces of legislation governing the health and social care sector. When it was introduced, the definition and scope of various care services was intended to vary depending on national need, as determined by the Health or Social care Minister.

According to the Act, an independent commission must register and inspect all care services against national care standards. These standards are to be taken into account when the commission makes any decisions about registering and inspecting services and in considering whether, and at what level, enforcement action should be taken. With this Act, for the first time, all local authority care services were required to register and to meet the same standards as independent sector providers. Failure of a care service or an individual to comply with the Act and

associated regulations means they can be de-registered and are no longer able to provide services.

Two new independent regulatory bodies were formed as a result of the Regulation of Care (Scotland) Act, which would ensure the registration and inspection of care providers to improve national quality standards. These were the Scottish Commission for the Regulation of Care (replaced by the Care Inspectorate in 2011) and the Scottish Social Services Council (SSSC). The primary aim of these independent bodies was to regulate the social services sector, including the regulation of social care workers and the education and training of the social services workforce.

### **3.3.7.2 The Community Care and Health (Scotland) Act 2002**

This Act introduced two new changes to the home support sector. These were:

1. the introduction of free personal care for older people, regardless of income or whether they live at home or in residential care, and
2. the creation of rights for informal or unpaid carers, with the intention of providing adequate support services to ensure the continuation of care-giving in the community.

The Act created the right to a separate carer's assessment and the responsibility of health boards to produce 'carer information strategies' which must be submitted free of charge to carers. The Act was amended in June 2018 (The Community Care (Personal Care and Nursing Care) (Scotland) Amendment (Regulations) 2018) as Parliament agreed to extend free personal care to people under the age of 65, effective by 1 April 2019.

### **3.3.7.3 The Carers (Scotland) Act 2016**

The Carers (Scotland) Act 2016 was passed in the Scottish Parliament on 4 February 2016. The Act came in to effect on 1 April 2018 and aims to ensure better and more consistent support for unpaid carers and young carers. The Act is designed to support carers' health and wellbeing and help make caring more sustainable.

The key duty in the Act is that carers who meet eligibility criteria must be provided with support to meet their identified needs. When carers do not meet eligibility criteria for support, local authorities must set out how they will meet those needs. Each local authority must set their own local eligibility criteria, and must consult and involve carers and representative organisations when developing the criteria.

#### **3.3.7.4 The Adults with Incapacity Act 2000**

The Adults with Incapacity (Scotland) Act 2000 provides ways to protect and safeguard the welfare and finances of adults who lack capacity to take some or all decisions for themselves. The Act also aims to support the involvement of vulnerable adults in making decisions about their own lives, as far as they are able to do so.

#### **3.3.7.5 Adult Support and Protection (Scotland) Act 2007**

The Adult Support and Protection Act 2007 gives greater protection to adults at risk of harm or neglect. It places a duty on local councils to inquire and investigate cases where harm is known or suspected. They have powers to visit and interview people, arrange medical examinations, examine records, and issue protection orders. They must also consider if there is any need for advocacy and other services, such as help with medication or support services.

#### **3.3.7.6 The Social Care (Self-directed Support) (Scotland) Act 2013**

The Social Care (Self-directed Support) (Scotland) Act 2013 has allowed people accessing social care services to have more control and choice over the type and degree of care and support they can obtain. This Act made it compulsory for all Local Authorities to offer prospective service users at least four named options for the delivery of their care and support.

#### **3.3.7.7 Social Work (Scotland) Act 1968**

Local councils have a duty under the Social Work (Scotland) Act 1968 to assess a person's community care needs and decide whether to arrange any services. Any assistance should be based on an assessment of the person's care needs and should take account of their preferences.

#### **3.3.7.8 Public Services Reform (Scotland) Act 2010**

The aim of this Act was to simplify and clarify the roles and responsibilities of various public bodies. As a result of this Act, the Scottish Commission for the Regulation of Care was dissolved and replaced by Social Care and Social Work Improvement Scotland (SCSWIS), later renamed as the Care Inspectorate.

#### **3.3.7.9 The Public Bodies (Joint Working) (Scotland) Act 2014**

The Public Bodies (Joint Working) (Scotland) Act 2014 sets the framework for integrating adult health and social care, to ensure a consistent provision of quality, sustainable care services for the increasing numbers of people in Scotland who need joined-up support and care, particularly people with multiple, complex, long-term conditions. The Act requires that local authorities and NHS Boards work together to

prepare a joint Integration Scheme, which sets out how health and social care integration should be planned, delivered and monitored within each local area. The Act also sets out national outcomes which apply across health and social care, focused on health and wellbeing. The NHS Boards and local authorities are held jointly accountable for the achievement of these outcomes.

This Act also established the role of the Care Inspectorate and Healthcare Improvement Scotland in working together to evaluate the effectiveness of the new integrated landscape and support improvement.

### **3.3.8 Regulation**

This section describes how home support services in Scotland are regulated by two independent but government-funded organisations: The Care Inspectorate and Healthcare Improvement Scotland.

#### **3.3.8.1 The Care Inspectorate**

Any organisation or person providing personal care and personal support to people in their own homes must register with the Care Inspectorate as a 'support service - care at home'. Where there is a personal and private arrangement (for example, personal assistants), or where the care is provided by a hospital as part of its continued healthcare service, this does not have to be registered with the Care Inspectorate.<sup>(78)</sup> The Care Inspectorate use the Health and Social Care Standards 2018 to assess home support service providers as to their suitability for first registration and annual re-registration.<sup>(97)</sup>

The Care Inspectorate produced a guide for newly-registering care services, which outlines the step-by-step process a care service will go through in order to be registered and legally operate a care service for care recipients in a home or community setting.<sup>(98)</sup> The completion of an application form is required. The information provided in the completed application form enables the Care Inspectorate to assess the following:

1. The suitability of the applicant and whether they can provide an adequate care service
2. The suitability of the premises in providing care services
3. If the proposed care service has adequate provisions in place to uphold the health, independence, welfare, dignity, choice and privacy of care recipients who will use the service.

The application process includes answering questions on how applicants plan to regulate and evaluate their home support services in the future, and it also seeks information on how they plan to involve staff and service users in this process.

When a service does not achieve the standards of quality and safety outlined in the national standards, the Care Inspectorate supports them by highlighting key areas for improvement according to nationally agreed quality indicators.<sup>(79)</sup> If the findings of an inspection are particularly poor, the Care Inspectorate may issue improvement orders, revoke the registration status of the service provider after a notice period, or attach conditions to their registration, requiring the provider to operate in a certain way. In cases where the service needs to be closed immediately, the Care Inspectorate must make an application to the Scottish courts for an emergency revocation of registration status.<sup>(99)</sup>

The results of inspection reports of individual care services are published and presented in a table online for a period of four weeks after the inspection. An overview of inspections carried out in each health board are published on a yearly basis. If a care service is performing particularly poorly or indeed particularly well, the Care Inspectorate will occasionally publish a highlight or feature about the findings from the inspection as a permanent fixture on their website.

### **3.3.8.2 Healthcare Improvement Scotland**

The purpose of Healthcare Improvement Scotland (HIS) is to enable the people of Scotland to experience the best quality of health and social care. This includes the regulation of healthcare settings, independent hospitals and clinics. The organisation inspects and monitors healthcare settings and carries out research producing evidence-based frameworks and guidance.<sup>(100)</sup> Healthcare Improvement Scotland have published a quality framework on achieving person-centredness in health and social care.<sup>(101)</sup>

The Care Inspectorate and Healthcare Improvement Scotland work together to carry out joint inspections of adult health and social care services for monitoring and supporting health and social care integration. The joint inspection process aims to determine how effectively health and social care services work in partnership, including the third and independent sectors, to deliver good outcomes for people using these services.<sup>(102)</sup>

### **3.3.9 Standards, guidance policies and frameworks**

This section examines the standards, guidance, policies and frameworks relevant to home support services in Scotland.

### 3.3.9.1 Standards

This section describes the standards in place in Scotland against which the quality and safety of home support services are assessed. Two sets of National Standards are described, these are the National Care Standards 2011, which are no longer in place, and the Health and Social Care Standards 2018. This section will also explore the ways in which these standards have been implemented, how this implementation has been supported, findings from reviews or evaluations, as well as barriers and facilitators.

As per The Regulation of Care (Scotland) Act 2001, home support providers should adhere to national standards for safety and quality in health and social care services, set by an independent regulatory commission or 'scrutiny body.' At the time of enactment of this act, these were the National Care Standards, which comprised multiple sets of fixed purpose standards. The National Care Standards were replaced in 2018 by the Health and Social Care Standards, which sought to provide one overarching set of standards that would apply to all health and social care services in Scotland.

The 2018 Health and Social Care Standards must be taken into account by the Care Inspectorate, Healthcare Improvement Scotland and other bodies that carry out inspections and registrations of health and social care services. The Standards must also be considered when making any decisions related to the registration, inspection and enforcement of improvement measures in respect of care services. As per the Act, the standards cannot be amended without consultation with relevant working groups.

#### **National Care Standards: Care at Home (2011)**

The National Care Standards were used to monitor the quality of services and their compliance with the Regulation of Care Act and regulations. They were replaced in 2018 by the Health and Social Care Standards. Although the National Care Standards are no longer in place, a brief explanation of these has been included in this review for information purposes.

The National Care Standards were developed from the point of view of people who use the services. They described what each individual person can expect from the service provider. They focused on the quality of life that the person using the service actually experiences. In the context of care at home, this included standards for:

- Lifestyle
- Eating well

- Keeping well - healthcare
- Keeping well - medication
- Private life
- Supporting communication
- Expressing your views.

When things went wrong in terms of home support service provision or delivery, people receiving services could refer to the standards when making an official complaint to the inspectorate. Service providers also used the standards to find out what was expected of them in offering care services in a person's home, and in employing people to carry out these services on a daily basis.

### **Health and Social Care Standards: My support, my life (2018)**

The Health and Social Care Standards (the Standards) set out what a person receiving care and support should expect when using health, social care or social work services in Scotland. They seek to provide better outcomes for everyone, to ensure that individuals are treated with respect and dignity, and that the basic human rights we are all entitled to are upheld. The objectives of the Standards are to drive improvement, promote flexibility and encourage innovation in how people are cared for and supported. All services and support organisations, whether registered or not, should use the Standards as a guideline for how to achieve high quality care.

These overarching standards replaced the National Care Standards to cover housing support and care at home for adults. The Standards are built upon five principles;

- dignity and respect
- compassion
- be included
- responsive care and support
- wellbeing.

The Health and Social Care Standards were developed to make health, social care and social work services better for everyone, so that every person is treated with respect and dignity, and their human rights which everyone is entitled to, are upheld.

The strategy for implementation of the standards in this context involved blending regulated service and strategic inspection methodology. The Care Inspectorate has been embedding the Standards in a variety of ways, including incorporating the

Standards into quality frameworks for inspections and support tools for service providers.

As part of the implementation process, the Care Inspectorate worked with carers' organisations to understand how the standards will impact on them and carers, and jointly produced a film and booklet about the standards.<sup>(103)</sup>

### **3.3.9.2 Guidance and implementation support tools**

This section outlines the guidance and implementation support tools that have been developed to support the Health and Social Care Standards and home support services in Scotland.

#### **Report on Implementation of the Health and Social Care Standards 2019**

In November 2019, the Care Inspectorate published a report on implementation of the Health and Social Care Standards. This report aimed to update the Scottish Government on the extent to which the Standards have been embedded into the inspectorate's improvement support and scrutiny and assurance activities, and also to promote the Standards across the organisation.<sup>(104)</sup>

#### **The Care at Home Hub**

The Care Inspectorate has published resources for people receiving home support, which can be found on a dedicated 'Care at Home' hub.<sup>(105)</sup> These resources include personal accounts from real people accessing these services. This allows consideration of the person's voice and experiences when deciding upon which care services to use.

#### **You Are Our Eyes and Ears**

In 2018, the Care Inspectorate, in collaboration with the terminal illness advocacy group Sue Ryder, published pocket guidance for what can be expected during a home support visit. This guidance, called 'You are our eyes and ears,' outlines in detail what prompts the home support worker should use, and specific observations they should be aware of. This was developed using the model of improvement approach (Plan, Do, Study, Act) in order to test a new way of documenting the condition of clients at each home visit, to pick up on any deterioration and alert older people so they can enable faster access to assessment and treatment.<sup>(106, 107)</sup>

### **3.3.9.3 Strategies and frameworks**

This section outlines the strategy and frameworks relevant to supporting the quality of home support services in Scotland.

## Reshaping Care for Older People

In 2011, the Scottish Government published 'Reshaping Care for Older People', a 10-year policy programme, with the primary aim of creating a greater system of support to improve the independence and well-being of the elderly in their homes and to substantiate a shift in the focus of care away from an institutional setting.<sup>(86)</sup>

### The Care Inspectorate Quality Frameworks

The Care Inspectorate monitors and inspects all care services in Scotland against quality frameworks which were developed in line with the Health and Social Care Standards, and informed by a human rights and wellbeing-based approach.<sup>(97)</sup> The same frameworks are also incorporated into self-assessment forms, in order to allow providers to use the same quality indicators that inspectors use when undertaking their own self-evaluation and quality assurance.<sup>(103)</sup>

The quality frameworks set out key questions that are asked of the service-provider about the difference a care service makes to people's wellbeing, and the quality of the elements that contribute to that.<sup>(108)</sup> These key questions include:

- How well do we support people's wellbeing?
- How good is our leadership?
- How good is our staff team?
- How good is our setting?
- How well is our care and support planned?
- What is our overall capacity for improvement?

Under each key question, there are three or four quality indicators, covering specific areas of practice (see Figure 3.1).

**Figure 3.1: The Quality Indicator Framework, Care Inspectorate**

Key question 1: How well do we support people's wellbeing?	Key question 2: How good is our leadership?	Key question 3: How good is our staff team?	Key question 4: How good is our setting?	Key question 5: How well is our care planned?
1.1. People experience compassion, dignity and respect	2.1. Vision and values positively inform practice	3.1. Staff have been recruited well	Not currently assessed for this service type	5.1. Assessment and personal planning reflects people's outcomes and wishes
1.2. People get the most out of life	2.2. Quality assurance and improvement is led well	3.2. Staff have the right knowledge, competence and development to care for and support people		5.2. Carers, friends and family members are encouraged to be involved
1.3. People's health and wellbeing benefits from their care and support	2.3. Leaders collaborate to support people	3.3. Staffing arrangements are right and staff work well together		
1.4. People are getting the right service for them	2.4. Staff are led well			
<b>Key question 6: What is the overall capacity for improvement?</b>				
<b>Key question 7: How good is our care and support during the COVID-19 pandemic?</b>	7.1. People's health and wellbeing are supported and safeguarded during the COVID-19 pandemic	7.2. Infection prevention and control practices are safe for people experiencing care and staff	7.3. Leadership and staffing arrangements are responsive to the changing needs of people experiencing care	

**Source:** Care Inspectorate (2020). A quality framework for support services (care at home, including supported living models of support).<sup>(108)</sup>

Each quality indicator has example scenarios of what 'very good' quality would look like, and what 'weak' quality would look like. These scenarios or 'illustrations' are drawn from the Health and Social Care Standards but are not checklists or definitive descriptions. They are designed to help people understand the level of quality that is expected. Each quality indicator includes a 'scrutiny and improvement' toolbox. This includes examples of evidence of the quality of care provided. It also contains links to practice documents that will help services to drive their own improvement efforts. The quality framework used in inspecting home support services is the Support Services (Care at Home) Framework.<sup>(108)</sup> This framework also includes provisions that are specifically related to support services, including care at home. These

provisions are focused largely around maintaining the independence of the person receiving care at home, and making sure they are still enjoying their hobbies and interests.

### **3.3.10 Findings from reviews**

This section outlines findings from review of the delivery of home support services in Scotland, particularly in the context of the Health and Social Care Standards where this information was available.

#### **3.3.10.1 Independent Review of Adult Social Care, and the consultation on the National Care Service**

In 2020, an independent expert panel carried out an extensive review of adult social care services, including home support services in Scotland, in order to assess the requirement for an integrated national care service. This review was commissioned as part of commitments made in the Programme for Government to carry out reforms in the area of adult social care.<sup>(109)</sup> The review, which was published in February 2021, considers the needs of people accessing adult social care services, as well as the needs of people working in adult social care services, and incorporates learning from the lived experiences of these groups. The findings from this review are intended to inform how the sector can be reformed in a way that best supports people using services, providers and staff, and assesses the current progress in integrating health and social care.<sup>(110)</sup> The review recommended the creation of an integrated National Care Service.

In August 2021, the Scottish Government launched a consultation on the development of the National Care Service. This consultation sought views on:

- improving how care is planned and delivered in practice, including rights to breaks from caring and non-residential care charges
- the role and remit of the National Care Service
- what might be included in the scope of the National Care Service
- how Integration Joint Boards will be reformed to become Community Health and Social Care Boards
- ethical commissioning and improving the commissioning of care across Scotland
- improving regulation and scrutiny, and
- valuing and supporting people who work in social care.

The consultation ran until November 2021 and responses and an independent analysis were published on the Scottish Government website. These were also published in easy-to-read and British Sign Language (BSL) formats. Major findings

from the consultation revealed themes and priority areas for improvement, and found that 72% of respondents supported the formation of the National Care Services that includes children's services, healthcare, social care and social work, nursing, prisons, mental health and others. Amongst other general responses relating to terms of employment and pay, responses highlighted the need for additional training in homecare and support services in order to improve the experience for the people using the service.<sup>(111)</sup>

### **3.3.10.2 Care Opinion**

Care opinion is an online tool where people can share their personal experience of using adult health and social care. Feedback is then provided to the Care Inspectorate and other regulatory bodies.<sup>(88)</sup> The Scottish Government funded Care Opinion to provide a service across the NHS, and is available to all UK residents and linked on the Care Inspectorate website.

### **3.3.10.3 Audit Scotland**

Audit Scotland, as a public sector regulatory body, supports the improvement of public services by looking at how public money is spent, and whether policies are achieving desired outcomes for individuals and bodies. They carry out extensive work on Scotland's health and social care services, which face challenges from reducing budgets, increasing demand, and an ageing population.

Audit Scotland carried out a performance audit on home support services in Scotland in 2001. This audit found shortcomings in the formal review of home support services, integration of care, and the availability of support structures.<sup>(112)</sup> In 2008, as a result of focus group consultations with older people, Audit Scotland published a review on the experience of free care at home. Participants in this review raised concerns about the consistency and availability of personal care, and highlighted that many older people who provided payment did not know what they were paying for, or were not properly informed about the free statutory scheme.<sup>(113)</sup>

Although there have been no stand-alone reviews of home support services published by Audit Scotland since 2008, these services fall under the regular financial audits of health and social care that are performed by the organisation on a yearly basis. Furthermore, as the national priority has moved towards caring for people in their own homes where possible, as opposed to institutional settings, home support is reviewed as part of the ongoing progress reviews for integrating health and social care under the Programme for Government.<sup>(109)</sup> For example, an Audit Scotland review on health and social care services integration in 2018 noted a gradual increase in the percentage of people's time spent at home or in a homely setting at the end of their life.<sup>(114)</sup> The same review detailed local improvements

made as a result of integration efforts, including local organisations that offer advice and support for people of any age who need assistance or adaptations in order to live independently at home. These local improvements were noted in this report as an enhancement of early intervention and prevention efforts.

### **Social care briefing**

In January 2022, Audit Scotland published a joint briefing by the Accounts Commission and the Auditor General for Scotland. This briefing highlights issues and threats to the future sustainability of Scotland's social care system that will need to be addressed. These issues and threats have resulted from exacerbation of pressures on the social care system caused by the COVID-19 pandemic. The briefing states that some services are at crisis point in terms of staff shortages, retention of staff, terms of employment and people's and carers' perception of services.<sup>(115)</sup> In particular, the briefing reports that 59% of homecare and support services are experiencing staff vacancies. Surveys of homecare staff revealed that 78% feel that they do not get enough time with service users to deliver compassionate, dignified care, and 73% revealed that they have had to carry out training in their own free time. Homecare visits have been reduced to just 15 minutes, according to this briefing, due to focusing primarily on cost-saving measures. These short visits leads to staff focusing on completing tasks, with no time for building a relationship with the service-user. The briefing document recommends a shift in terms of how money is spent in the social care sector, with investment in early intervention and preventative strategies to meet the needs of individual people. Furthermore, the briefing calls on the Scottish government to prioritise implementation of the planned National Care Service, and to listen to the voices of social care staff, carers, and service-users. Additional audit work will take place in the sector in 2022-2023.<sup>(115)</sup>

#### **3.3.10.4 The King's Fund**

Adult social care services add value to the economy of Scotland, according to an audit published in 2016, by creating over 147,800 jobs. A report published by the King's Fund in 2018 identified Scotland's home support model as being more economically favourable than the current model being delivered in England.<sup>(87)</sup>

#### **3.3.10.5 Approaches to the regulation and financing of home support services in four European countries: An evidence review**

In 2017, the Health Research Board in Ireland carried out an evidence review on the regulation and financing of home support services across various jurisdictions, including Scotland.<sup>(116)</sup> This review drew overall positive conclusions on the ability of home support in Scotland to meet the needs of the population, however noted that the advocacy organisation Scottish Care have raised concerns about some aspects of

the sector, including policy direction and workforce planning. This review stated that while policy moving care away from institutional settings was welcome, it may be difficult to achieve, considering an increasingly aged population. Zero-hour contracts and poor job stability were noted as being barriers to retaining staff for providing home support in Scotland.<sup>(116)</sup>

### 3.3.10.6 NHS Scotland

Facilitating factors for implementing the model of home support delivery include the fact that it is a national priority. National policy and strategy identifies home support as a national priority in Scotland. For example, the Healthcare Quality Strategy aims to ensure that the work of the NHS in Scotland is integrated and aligned to deliver the highest quality health and care services. One of its six quality outcomes relates to people being able to live well at home or in the community so that the need for hospital admission is minimised.<sup>(78)</sup> Under the strategic aims of the NHS Scotland Reshaping Care for Older People Programme 2011-2021, care will increasingly be moved away from institutional settings in favour of prolonging the number of years that older people can live comfortably and independently in their own homes. Home support services are a central aspect in achieving this strategic aim by offering a preventative service, identifying problems before they lead to medical issues or hospital admissions. Home support services also improve an older person's quality of life by allowing them to remain in the environment that they are familiar with, where they can have control over their surroundings, the people they interact with, and the activities that they choose to do. These strategic aims are reflected in the three key principles of the 'Reshaping Care for Older People' programme. These are:

1. **Personalisation:** Service users and carers must be at the centre of what we do. We recognise that older people are a diverse group of individuals with their own cultures, needs and choices.
2. **Independence:** Where possible, we need to make sure older people are supported to live independently, preferably in their own home. But if they do need a care home or hospital, it must meet their care needs. Introducing choice adds to a person's independence and gives them ownership of the decision. For example, the individual chooses their own care provider.
3. **Control:** Rather than having decisions made for them, we want older people who require care services to make their own decisions.<sup>(86)</sup>

### 3.3.10.7 Changes due to COVID-19 pandemic

This section outlines the barriers that may restrict the delivery of home support services in Scotland as a result of the COVID-19 pandemic. There was limited

information available on specific facilitating factors for implementation of the Health and Social Care Standards.

The delivery of home support has been challenged by the COVID-19 pandemic. The first wave of infections led to the suspension of home support services in May 2020, resulting in a pause in access to home support services for thousands of Scottish residents.

In August 2020, Health Protection Scotland published guidance to support those working in domiciliary care settings to give advice to their staff and users of their services about COVID-19. This includes registered providers, social care staff, local authorities and care staff who support and deliver care to people in their own homes (including supported living settings).<sup>(117)</sup> This guidance includes specific measures targeted at people receiving home support who have a COVID-19 positive household member, and also people who are receiving home support as a result of their discharge from COVID-19 treatment.

The Care Inspectorate made changes to the way it inspects care services as a result of COVID-19. These changes, made as a result of the Coronavirus (Scotland) (No. 2) Act 2020, place particular focus on infection prevention and control, wellbeing and staffing in care settings. This means carrying out targeted inspections that are short, focused and carried out with colleagues from Health Improvement Scotland and Health Protection Scotland, to assess care and support during the COVID-19 pandemic.<sup>(118)</sup> As a result, a seventh 'key question' was added to all quality frameworks used by the care inspectorate: "How good is our care and support during the COVID-19 pandemic?"

In December 2020, the Care Inspectorate published a self-evaluation tool and guidance for older people and adult services to assess how well these care services are doing during the COVID-19 pandemic and identify and support improvements in outcomes for people. This tool is intended to be used in conjunction with the quality framework for each service type and the Care Inspectorate guide to self-evaluation, both of which are designed to support services to self-evaluate.<sup>(119)</sup>

### **3.3.11 Summary and Lessons for Ireland**

In Scotland, home support, or care at home, is provided free to all people over 65 and other people with illnesses or conditions that limit their ability to live independently at home. This free personal and nursing care is a statutory entitlement outlined and defined in legislation, and monitored against National Standards. As such, Scottish home support is backed by a strong regulatory framework and has clearly-defined boundaries in terms of what tasks are included and how services and their workforce are regulated. Placing homecare services on a

statutory footing, as in Scotland, would give people an entitlement to the service should people meet certain eligibility criteria. Regulating the home support sector in Ireland in a similar way may reduce confusion in the sector and provide further stability to the workforce.

Home support providers in Scotland must take consideration of the Health and Social Care standards. The Care Inspectorate, which monitors and inspects the quality of home support, use these standards in assessing the quality of services and incorporate the principles of the standards into their assessment framework. There are currently no national quality standards in relation to the provision of homecare in Ireland. The Health and Social Care Standards in Scotland are high-level, overarching standards, and use language that was developed with the daily implementation of the standards in mind. As a result, the standards can be adaptable to situations that people providing care at home experience in their daily work, and can implement the standards more naturally as they are familiar with and already use the language of the standards.

Nursing care is not a registerable activity with the Care Inspectorate, and is often not within the scope of services provided to a person receiving care in their own homes. Not having nursing care included in the scope of services may present difficulties as homecare becomes increasingly in demand due to an ageing population, and it may be restrictive to exclude nursing care. Where nursing care is provided, this is generally as a result of local NHS partnerships established under the provisions of the Public Bodies (Joint Working) Act 2014 and is under the remit of the Healthcare Inspectorate. These NHS partnerships, which may vary between local authorities, highlight the principle of integrated care in Scotland. Placing a greater emphasis on integration between primary, community and acute care, as per the Scottish approach, may allow more people in Ireland to live independently at home.

It is important that all potential recipients of homecare can be assessed using the same criteria. The national eligibility framework in Scotland is an example of this. Care needs assessments should place the care recipient at the centre of the process and should also incorporate the views of their family and or representatives as well as their community and primary caregivers. The assessments should also include an applicant's needs in terms of rehabilitation and re-ablement. Having such a focus in Irish home support would have a dual benefit of providing support to the person in their own home, whilst also improving their capacity to care for themselves, thereby reducing their dependence on support. These assessments, like those in Scotland, should be subject to regular review, to identify a person's changing care needs as they emerge.

The Quality Frameworks against which the Care Inspectorate monitor and inspect home support services adopt an outcomes-focused approach, where a holistic view of the person receiving care and support is emphasised. Having such a focus may ensure that inspections of care at home services are not restricted to a compliance versus non-compliance approach, which may result in some aspects of care and support delivery, such as the person's wellbeing and quality of life, being overlooked as indicators of how well the service is performing. Furthermore, an outcomes-focused approach may highlight the importance of the person's voice in the inspection process. As a result, it would be useful for the development of inspection frameworks to involve consultation with people experienced in delivering and receiving care at home.

## 3.4 England

### 3.4.1 Overview of home support services

Free or part-funded home support services are available in England to all those who meet certain financial and eligibility requirements, as determined by means testing and needs assessments. Service users include children and adults with disabilities and older people. Care may be delivered for a short period of time following a stay in hospital (for example, re-ablement) or long-term, for ongoing support needs.<sup>(87)</sup>

Home support services are known as homecare or domiciliary care in England. In 2015, it was estimated that more than 350,000 older people in England were using home support services, 257,000 (73%) of whom had their care paid for by their local authority. A further 76,300 younger people with learning disabilities, physical disabilities or mental health complaints were also estimated to be using publicly-funded home support.<sup>(120)</sup> The term 'older person' is not specifically defined in English health and social care services, as per the NHS Improving Care for Older People strategy.<sup>(121)</sup> According to this strategy:

Generally, someone over the age of 65 might be considered an older person. However, it is not easy to apply a strict definition because people can biologically age at different rates so, for example, someone aged 75 may be healthier than someone aged 60. Instead of simply age, 'frailty' has a bigger impact on their likelihood to require care and support.

Demand for home support in England is forecast to increase significantly. Older users of local authority-funded home support are predicted to rise by 82% from 257,000 in 2015 to 468,000 in 2035. Users of privately-funded home support are projected to rise by 49% over the same period, while younger adults with learning disabilities using home support are predicted to rise by 51%. Importantly to note, at a time when population projections might indicate a rise in demand for social care, the amount local authorities are spending and the number of people eligible for local authority-funded home support are falling due to budgetary constraints.<sup>(87)</sup>

### 3.4.2 Model of home support service delivery

This section outlines the model of home support services in England, and how these services are delivered, supported, and governed. This section will include:

- Structure and governance
- scope
- eligibility and assessment of need
- funding and commissioning
- workforce

- legislation
- regulation.

### 3.4.3 Structure and governance

In England, home support is a statutory responsibility of social service departments and NHS local councils, who must provide or commission services to people who have been determined to require them, based on a care needs assessment. This care is not always provided fully free of charge, and is subject to financial means testing by local authorities, where people generally have to pay for part or all of their care if they can afford it. The United Kingdom Homecare Association (UKHCA) estimated in 2015 that around 249 million hours of home support are delivered in England each year, by around 680,000 members of staff, across various public and privately-owned agencies. <sup>(122)</sup>

Home support is central to the aim of the NHS strategy, *Improving Care for Older People*, of "helping frail and older people stay healthy and independent, avoiding hospital stays where possible."<sup>(121)</sup> Under the Care Act 2014, local authorities and NHS local health boards have a statutory duty to ensure that there are sufficient services of a sufficiently high quality to meet people's needs. Currently there are increasingly long waiting times for home support packages for people ready to leave NHS hospitals, which is a significant cause of delayed discharges.<sup>(121)</sup> However, the length of wait varies significantly between NHS local boards. As the single largest purchaser of home support, local authorities have significant influence on markets and there is wide variation between them, which is evidenced by wide variations in the rates paid for care.<sup>(87)</sup>

Home support service providers in England must be registered with the Care Quality Commission (CQC).<sup>(123)</sup> The CQC is the independent regulator of care in England. They monitor, inspect and regulate home support services to make sure they meet fundamental standards of quality and safety. The CQC publish the findings from these inspections, naming the provider and including performance ratings, which can help people choose care.<sup>(124)</sup>

The National Institute for Health and Care Excellence (NICE) provides national guidance and advice to improve health and social care.<sup>(125)</sup> NICE's role is to improve outcomes for people using the NHS and other public health and social care services. They do this by:

- Producing evidence-based guidance and advice for health, public health and social care practitioners.

- Developing quality standards and performance metrics for those providing and commissioning health, public health and social care services.
- Providing a range of information services for commissioners, practitioners and managers across health and social care.

The Homecare Association, formerly known as the United Kingdom Homecare Association or UKHCA, is the professional association of home support providers from the independent, voluntary, not-for-profit and statutory sectors. The UKHCA helps organisations that provide home support services to people in their own homes, promoting high standards of care and providing representation with national and regional policy-makers and regulators. It is member-led, and represents over two-thousand members across the United Kingdom, in England, Wales, Scotland and Northern Ireland. UKHCA's business strategy looks to support homecare providers to deliver sustainable, high quality, responsive services, while also helping them to manage current and future challenges and opportunities.<sup>(122)</sup>

Independent Age, which is an advocacy group supporting older persons to live independently, produce guides for older people on home support, including how to choose the right service and how to receive a needs assessment. These guides, aimed at the older person, are written in plain English and are free of technical or clinical language where possible. The guides are also available in audio format and easily accessible for free on the Independent Age website.

#### **3.4.4 Scope and definitions of home support**

This section outlines the scope of home support services available in England, and the definitions of care and support and various tasks that are used.

Home support services in England are provided to people who still live in their own homes but require additional support with activities, including household tasks, personal care and any other activity that allows them to maintain both their independence and quality of life.<sup>(123)</sup>

The term 'home support' covers a wide range of activities. The provision of personal care (help with washing, dressing and eating) to people with long-term care needs is the core service provided by most local authorities, but home support also extends to treatment of disease, disorder, and injury, nursing care, and re-ablement services for people leaving hospital or receiving crisis interventions, to avoid hospital attendance in the first place. Services that provide personal care, and should therefore be registered as such with the CQC, include:

- Domiciliary care agencies (homecare)

- Extra care housing
- Shared Lives scheme
- Supported living.

The CQC describes the regulated activity 'personal care' as supporting people in their homes (or where they are living at the time) with things like washing, bathing or cleaning themselves, getting dressed or going to the toilet. It does not include household tasks.<sup>(126)</sup> If nursing care is being provided, it is registerable with the CQC under the activity TDDI. Nursing care, according to the CQC and the Health and Social Care Act 2012, means any service provided by a nurse involving either:

- the provision of care, or
- the planning, supervision or delegation of the provision of care, other than any services which, by their nature and the circumstances in which they are provided, do not need to be provided by a nurse.

While the term 'home support' can also include help with household tasks, under the eligibility guidelines applied in England, the requirement for these alone would not entitle people to local authority help and, in most cases, would need to be paid for privately. The CQC does not regulate or inspect against the provision of household tasks, but can extend their key lines of enquiry to these.<sup>(127)</sup> Some home support is also provided on a 'live-in' basis.<sup>(120)</sup> Specialist care teams, GP visits, OT visits, district nurses and so on would not usually be included under personal care or TDDI. This is generally under community care services.

Regular home visits from a fully trained care worker, from 30 minutes through to several hours a day, can be arranged to help people with a wide range of everyday tasks, including:

- personal and continence care
- managing medication
- help from a care worker with tasks like washing, dressing or taking medication
- helping to mobilise in and around the home
- household tasks and meal preparation
- clinical care, including catheter and stoma management and PEG feeding
- disability equipment or adaptations to a home, such as a stair-lift
- telecare, such as a bed sensor or wearable alarm
- meals on wheels.

In addition, home support visits offer a source of companionship for the person receiving care. Some providers offer overnight support, or 24-hour live-in care, however most care plans are built around a 30 minute visit per day.<sup>(121)</sup>

Household tasks are not regulated in England, but the CQC have key lines of enquiry which they use for assessment of home support services and these may extend to a more holistic view of care and support.<sup>(127)</sup>

### 3.4.5 Eligibility and assessment of need

This section describes how eligibility and priority for care and support is assessed in England, through a standardised process set out in legislation.

As previously stated, the number of people receiving state-funded care in England is falling. This decrease in overall numbers has been attributed to the fact that the statutory sector is targeting services to those who need more intensive support, rather than those with lower level needs.<sup>(120)</sup> With an overall pattern of tightening 'eligibility' criteria, it is now estimated that around 72% of councils only offer homecare services to those with 'substantial' or 'critical' needs. A recent study estimated that around 450,000 older people in need of care have some sort of shortfall in the formal care they receive, with 275,000 older people with less intensive needs getting no support from their local council.<sup>(120)</sup>

The Care Act 2014 creates a national minimum eligibility threshold across England.<sup>(128)</sup> Where an adult's or carer's needs reach this threshold, the local authority must consider how these needs can be met and, depending on their financial means, the local authority may be under a duty to provide services to meet these eligible needs. The Care Act 2014 outlines eligibility criteria for adults with care and support needs, which care assessments should be based on. These criteria are outlined below at Table 3.1.

**Table 3.1: Eligibility criteria for adults with care and support needs under the Care Act 2014**

Condition		Explanation
1	The adult's needs for care and support arise from or are related to a physical or mental impairment or illness and are not caused by other circumstantial factors.	This includes if the adult has a condition as a result of physical, mental, sensory, learning or cognitive disabilities or illnesses, substance misuse or brain injury.
2	As a result of the adult's needs, the adult is unable to achieve two or more of the outcomes specified in	Local authorities must also be aware that 'being unable' to achieve an outcome includes any circumstances where the adult is:

	<p>the regulations and outlined in the section 'Eligibility outcomes for adults with care and support needs'.</p>	<ul style="list-style-type: none"> <li>▪ Unable to achieve the outcome without assistance. This includes where an adult would be unable to do so even when assistance is provided. It also includes where the adult may need prompting. For example, some adults may be physically able to wash but need reminding of the importance of personal hygiene.</li> <li>▪ able to achieve the outcome without assistance, but doing so causes the adult significant pain, distress or anxiety. For example, an older individual with severe arthritis may be able to prepare a meal, but doing so will leave them in severe pain and unable to eat the meal.</li> <li>▪ able to achieve the outcome without assistance, but doing so endangers or is likely to endanger the health or safety of the adult, or of others. This would include, for example, situations where the health or safety of another member of the family, including a child, could be endangered when an adult attempts to complete a task or an activity without relevant support;</li> <li>▪ able to achieve the outcome without assistance but takes significantly longer than would normally be expected. For example, a physically disabled adult is able to dress themselves in the morning, but it takes them a long time to do this, leaves them exhausted and prevents them from achieving other outcomes.</li> </ul> <p>Local authorities must consider the whole range of outcomes contained in the criteria when making the eligibility determination. There is no hierarchy to the eligibility outcomes – all are equally important.</p>
<p>3</p>	<p>As a consequence of being unable to achieve these outcomes, there is, or</p>	<p>Local authorities should determine whether:</p> <ul style="list-style-type: none"> <li>▪ the adult's needs impact on at least one of the areas of wellbeing in a significant way or</li> </ul>

	there is likely to be, a significant impact on the adult's wellbeing.	<ul style="list-style-type: none"> <li>▪ the cumulative effect of the impact on a number of the areas of wellbeing means that they have a significant impact on the adult's overall wellbeing.</li> </ul>
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**Source:** Government of the United Kingdom (2014). The Care Act.<sup>(129)</sup>

A care needs assessment determines what help or support a person needs with their care, and how they might get it. It is usually provided by the social services department of local councils. The council has to provide an assessment if a person appears to need care and support, regardless of their income or savings or whether the council thinks they will qualify.<sup>(121)</sup> The assessment is described on the NHS website as "a chance to discuss what support [you] need with a trained professional." After an assessment, the council gives the person a copy of their care needs assessment and explains what their care needs are.<sup>(130)</sup> There are no set timescales for carrying out an assessment, but according to the NHS website this should ideally happen within a reasonable time and take into account the urgency of the situation. If a person is struggling and requires an urgent assessment, they may be able to receive an emergency care package which can meet their care needs until a full assessment can be done.

### 3.4.6 Funding

This section describes how home support services in England are funded and commissioned by local authorities, and how eligibility for funding is assessed. Local councils may contribute to the cost of the homecare service, as determined by a needs assessment. If eligible, the council recommend care at home and then arrange the homecare service and contribute to the cost, also known as state-funded homecare.<sup>(131)</sup> The council determine how much the person needs to contribute to homecare costs in a financial assessment, also known as a means test. How much each person pays depends on their salary and savings. Council funding for social care is derived from the revenue support grant received from central government, from locally generated incomes such as council tax and business rates, and from user charges.<sup>(132)</sup>

As part of the means test process, a Financial Assessment Officer visits the person's home and examines their earnings, pensions, benefits and savings. For home support services, the value of a person's home is not included in the financial needs assessment.<sup>(133)</sup> A person being assessed for care at home should be treated as an individual, so if care is being sought for a married couple or a person living with a partner, only the income of the 'cared-for' person can be taken into account in the financial assessment.<sup>(133)</sup>

- If the person's capital is over £23,250, they will have to pay for the homecare service in full.
- If they have between £14,250 and £23,250, the council will contribute some of the money required.
- If they have less than £14,250, capital won't be included in the test and the council will pay for care but will take any eligible income into account. <sup>(131)</sup>

The homecare market in England is valued at £5.5 billion annually, covering approximately six million hours a week. Public spending accounts for £2.2 billion of this figure and the rest is privately funded, although some of the privately funded care is publicly provided, where private and voluntary sectors supply 84% of this. <sup>(134)</sup> There has been a trend in England over recent years for NHS Clinical Commissioning Groups (CCG) to purchase social care and health services from the independent and voluntary sector. In 2014/15 total CCG expenditure on non-NHS care services was £2.3 billion. <sup>(135)</sup>

The cost of homecare is forecast to rise from 1% of the UK's Gross Domestic Product (GDP) now, to between 2% and 4% by 2050 (GDP being the total market value of all final goods and services produced in a country in a given year). <sup>(134)</sup>

Funding cuts continue to have an impact on homecare services, with commissioners finding that they are having to drive down costs to meet their own restricted budgets. <sup>(134)</sup>

### **3.4.6.1 Adult Social Care Charging Reform**

In late 2021, the government announced changes to the ways that people will be charged for adult social care, including homecare, over their lifetime. This introduced lifetime caps on how much a person can be charged for personal care, and expanded the criteria for means testing by local authorities. <sup>(136)</sup>

According to the report, by October 2023 the government will introduce a new £86,000 cap on the amount any adult, of any age in England will need to spend on their personal care over their lifetime. In addition, the upper capital limit (UCL), the point at which people become eligible to receive some financial support from their local authority, will rise to £100,000 from the current £23,250. As a result, people with less than £100,000 of chargeable assets will never contribute more than 20% of these assets per year. The UCL of £100,000 will apply universally, irrespective of the circumstances or setting in which an individual receives care. Furthermore, the threshold below which people will not have to pay anything for their care from their assets will increase to £20,000 from £14,250. <sup>(136)</sup> The government will unfreeze the Minimum Income Guarantee (MIG) for those receiving care in their own homes so that from April 2022 it will rise in line with inflation.

### 3.4.7 Workforce

The home support services workforce in England is not regulated. In England, unlike other countries in the UK, there are currently no formal requirements for registration of staff working in home support services. The only training and qualification requirements for general domiciliary care staff are the completion of the Care Certificate, which has been a requirement since the 2013 Cavendish Review of the NHS and social care services.<sup>(137)</sup>

The Care Certificate is an identified set of standards that health and social care professionals adhere to in their daily working life, and it sets out the introductory skills, knowledge and behaviours that health and social care professionals should follow to provide compassionate, safe and high-quality care and support, in their own particular workplace setting. The Care Certificate is based on 15 standards, which individuals need to complete in full before they can be awarded their certificate.<sup>(138)</sup>

According to a report published by the Social Care Institute for Excellence (SCIE), domiciliary care staff in England can be seen as poorly trained and poorly paid, which leads to high turnover of paid carers (32% leave within 12 months; 56% within two years). This can mean a lack of continuity of care for users and a lack of flexibility in changing care arrangements.<sup>(134)</sup> Around a quarter of the adult social care workforce were recorded in 2019 as being employed on a zero-hours contract (24%, or 375,000 jobs), and home support services had the highest proportion of workers employed on zero-hours contracts (42%), especially among care workers (56%).<sup>(139)</sup>

Recruitment and retention of staff is a particular challenge facing home support services in England, according to a 2018 report by the Kings Fund. Availability of staff is a difficulty in rural areas, where costs are also higher because of the additional travel time needed for workers to visit clients.<sup>(120)</sup>

Payment for domiciliary care staff in particular is complex, with employers able to pay different rates for contact time and non-contact time, provided that these average out above the national living wage. However, there are concerns that this complexity offers the potential to pay below statutory minimums, and a 2011 study estimated that between 9% and 13% of direct care workers might be affected. The average pay for independent sector care workers recorded by Skills for Care in 2016/17 was £7.76 per hour (compared to the then national living wage of £7.20), equivalent to an annual full-time equivalent (FTE) rate of £15,000.<sup>(132)</sup>

There is heavy reliance on informal care in England. According to data from the 2011 census, there were approximately 5.8 million people (5.4 million in England

alone) providing unpaid care in England and Wales, around 10% of the population. This was an increase of 600,000 since 2001.<sup>(132)</sup>

### **3.4.8 Legislation**

This section outlines the legislation that forms the regulatory framework for statutory home support services in England.

#### **3.4.8.1 The Care Act 2014**

The Care Act 2014 places a duty on local authorities to promote wellbeing and meet needs (rather than requiring them simply to provide services). It also requires local authorities to assess and offer support to address the needs of carers, independently of the person they care for.<sup>(129)</sup> People funding their own home support are also covered under this act.

The Care Act 2014 sets out local authorities' duties in relation to assessing people's needs and their eligibility for publicly-funded care and support. Under the Care Act 2014, local authorities must:

- Carry out an assessment of anyone who appears to require care and support, regardless of their likely eligibility for state-funded care.
- Focus the assessment on the person's needs and how they impact on their wellbeing, and the outcomes they want to achieve.
- Involve the person in the assessment and, where appropriate, their carer or someone else they nominate.
- Provide access to an independent advocate to support the person's involvement in the assessment, if required.
- Consider other things besides care services that can contribute to the desired outcomes (for example, preventive services and community support).
- Use the new national minimum threshold to judge eligibility for -funded care and support.

The eligibility criteria for adults with care and support needs are outlined in the Care Act 2014, and are included above in Table 3.1. As well as this, the act outlines eligibility criteria for carers requiring support, with the aim of protecting the carer's wellbeing and mental health, if these are deteriorating as a result of their work.

Statutory guidance was published alongside the Care Act 2014 as an implementation support tool.<sup>(140)</sup> Furthermore, SCIE offer training and accredited courses on their website, aimed at helping care providers and staff to implement the Care Act 2014 in their daily work.<sup>(133)</sup>

A plan to amend the Care Act 2014 to implement adult social care reforms was announced in late 2021 as part of the 'Build Back Better' plan for health and social care.<sup>(141)</sup> As of February 2022, this legislation has not yet been published.

### **3.4.8.2 The Health and Social Care Acts 2008 and 2012**

The Health and Social Care Act 2008 specifies the statutory regulator (CQC), statutory registration and the standards for inspection. The CQC regulate personal care and TDDI (including nursing care) under the Health and Social Care Act 2008, and produce guidance which articulates what is expected of providers against this legislation.<sup>(142)</sup>

The 2008 act was updated, but not replaced, by a new supporting Health and Social Care Act in 2012.<sup>(143)</sup> The main aims of the 2012 act were to change how NHS care is commissioned through the greater involvement of clinicians and the NHS Commissioning Board, which is an independent body with executive powers that holds the government accountable for its plans for investment in the NHS. The Act created Public Health England, and takes forward measures to reform health public bodies.

### **3.4.9 Regulation**

This section describes how home support services in England are regulated by the CQC. It concludes with a description of how the work of the National Institute for Health and Care Excellence (NICE) supports the CQC in this role.

#### **3.4.9.1 The Care Quality Commission (CQC)**

The CQC is the independent regulator of health and adult social care in England. Since 2013, reforms have been made to the CQC's regulatory model and to the Department of Health's governing legislation to embed a new model across all the sectors it regulates, including adult social care. These planned reforms addressed a number of the findings of the government-commissioned *Focus on Enforcement Review*.<sup>(144)</sup> A consultation on this new approach to regulating, inspecting and rating community adult social care services concluded in June 2014. The intention proposed is that inspectors should use their professional judgment, supported by objective measures and evidence, to assess whether services are safe, effective, caring, responsive to people's needs and well led. Services will be rated to help people to compare them and to highlight where care is outstanding, good, requires improvement or is inadequate.<sup>(134)</sup>

The CQC adopts a service-based approach to regulation. The Health and Social Care Act is the basis for regulation of services by the CQC. It is the legal body (service

provider) that provides the regulated activity that must register with the CQC, as opposed to the location or care setting where it is carried out.

When the CQC carries out inspections, an overview of inspection findings is presented under five components,<sup>(127)</sup> which are:

- Safe
- Effective
- Caring
- Responsive
- Well led.

The degree to which the service meets these components is indicated by a green colour for 'good,' a red colour for 'inadequate,' or an orange colour meaning 'needs improvement', which makes the summary reports accessible and easy-to-read. If the service is performing particularly well in the context of one or more of these areas, they will receive a green star, which indicates that this particular component of the service was found to be 'outstanding.'<sup>(127)</sup>

The CQC published a guide on what can be expected of good home support services, which expands on these components in further detail and explains in plain English what these should look like in a high quality home support agency.<sup>(145)</sup> These explanations can be seen below at Table 3.2.

**Table 3.2: What to expect from a good home support agency (CQC)**

Component	Explanation
Safe	<p>You feel safe and protected by staff, but you also have as much freedom as possible to do the things you want to do – regardless of your disability or other needs.</p> <p>Staff protect your dignity and human rights and respect you as an individual. There are enough staff to make sure you receive a reliable service that is not rushed.</p> <p>Staff have the right mix of skills to make sure you are kept safe. If the person caring for you needs to change at short notice, you are told so that you know who to expect.</p> <p>You are protected from being bullied, harassed, harmed or abused. Abuse includes neglect and financial abuse.</p>

	<p>Staff deal with incidents and accidents quickly and openly (and investigate them if necessary) and they learn from mistakes.</p> <p>Staff give you your medicine safely and store it correctly. Where possible, the agency involves you in reviewing your medicines and supports you to be as independent as possible.</p> <p>Any equipment that the agency uses is well maintained. You should feel confident that your belongings are safe and secure.</p>
<p>Effective</p>	<p>You are introduced to any staff who are going to provide your care.</p> <p>The staff are chosen because they can provide you with the right care, based on their knowledge, qualifications and skills.</p> <p>You are always asked to give your consent (permission) to care, treatment and support in a way you can understand. If appropriate, your friends and family are also involved in decisions about your care.</p> <p>Staff take steps at the right time to make sure you stay in good health.</p> <p>Staff know about your health needs and personal preferences. They regularly involve you in decisions about your care and treatment and give you as much choice and control as possible.</p> <p>Staff make sure you get the right food and drink you need, and that you have enough of it.</p> <p>You are regularly asked for your views about the service you receive, and your feedback is consistently good.</p>
<p>Caring</p>	<p>Staff know about your background, likes, hopes and needs. This includes any needs you have because of your age, disability, sex (gender), gender identity, race, religion or belief, or sexuality (whether you are lesbian, gay, bisexual or heterosexual).</p> <p>You are encouraged to express your views, no matter how complex your needs are.</p> <p>You have access to advocates (people who can speak on your behalf).</p>

	<p>Staff treat you with dignity and respect. They have time to develop trusting relationships with you and are concerned for your wellbeing.</p>
<p>Responsive</p>	<p>Your care, treatment and support are set out in a written plan that describes what staff need to do to make sure you receive personalised care.</p> <p>You, and your family and friends where appropriate, are actively involved in developing this plan and it reflects your personal choices. For example, you should be able to have a choice about who provides you with personal care, such as help with washing and dressing.</p> <p>As your needs and preferences change, your plan is changed, and all those who need to know, like other services, are kept up to date.</p> <p>The plan includes information about the whole of your life, including your goals, your abilities and how you want to manage your health. You may also have a health action plan.</p> <p>If you need to visit hospital or use another service, staff plan this with you to make sure it goes as smoothly as possible.</p> <p>If you have any concerns or complaints, staff always take them seriously, investigate them thoroughly and respond to them in good time.</p>
<p>Well led</p>	<p>Staff know what is expected of them and are happy in their work.</p> <p>Staff are supported by their managers, and can easily meet other staff members to share views and information.</p> <p>Staff have the confidence to report any concerns they have about the care that colleagues, carers and other professionals give. When this happens they are supported and their concerns are thoroughly investigated.</p> <p>Staff and managers work effectively with others who may be involved in caring for you, such as your local council.</p> <p>Managers know what their responsibilities are and are always honest, including when things go wrong.</p>

**Source:** CQC (2017). What can you expect from a good home care agency?<sup>(145)</sup>

The provider of home support services, which can be an organisation, partnership or individual, must register with the CQC in order to provide care in people's homes. This means that if a home support worker is registered as an organisation or partnership, then the person responsible for managing the services must also register. If a home support worker registers as an individual, they don't need to have a separately registered manager unless they don't intend to be in charge full-time.<sup>(145)</sup>

Domiciliary care agencies are registered with the CQC under the 'personal care' regulated activity. Nursing care provided by domiciliary care agencies is registered under the regulated activity Treatment of Disease Disorder or Injury (TDDI). Each agency providing home support services must complete a 'statement of purpose' and must notify on standard operating procedures what type of care they deliver. If an agency provides both nursing care under TDDI and personal care, they have to register to carry out both of these regulated activities. The CQC have no powers of enforcement in terms of household tasks or accommodation.<sup>(124)</sup>

The CQC previously used a compliance versus non-compliance model of inspection against the regulations, however there was difficulty in matching each identified shortcoming to the regulation that was not being met. A ratings model is now used based on Key Lines of Enquiry (KLOEs), and these are not mapped to specific sections of the regulations. These KLOEs take a wider approach to monitoring quality that is not limited to the regulations.<sup>(127)</sup>

The CQC has developed seven human rights principles which it applies when regulating services against the 13 fundamental standards outlined in the Care Act 2014. These principles are based on the Fairness, Respect, Equality, Dignity and Autonomy (choice and control) or FREDAs principles. The CQC has added two further principles to its human rights approach to regulation, which are the 'human rights article of right to life', and a principle of 'staff rights and empowerment'. This latter addition was based on research that links staff empowerment to the quality of care they deliver.<sup>(146)</sup> The CQC applies these human rights-based principles to its five key questions it asks when reviewing health and social care services against the 13 fundamental standards.<sup>(147)</sup>

The CQC are currently in the process of changing the whole inspection framework for all sectors and service types. As of February 2022, the relevant updates to the inspection framework have not yet been published.

In 2021, following piloting of new methods of inspection, some changes were made to the way that the CQC inspects domiciliary care. In some cases, the CQC now use phone or online methods to help inspectors to carry out their work, meaning they do not always have to visit in person. These inspections are still carried out according to existing CQC policies and practices.<sup>(124)</sup>

### **Not just a number: Homecare inspection programme, National overview - CQC**

This 2013 report on a review of homecare services by the CQC in England outlines in detail the quality of care delivered to people in their own homes by regulated providers. The main concerns relating to respecting and involving people who use services included the lack of continuity of care workers, limited information to people about the choices available to them and failures to keep people informed about changes to their visits.<sup>(148)</sup> Other concerns that arose during this review included:

- Missed or late calls and inconsistent weekend services
- Lack of staff knowledge and skill, particularly with regard to dementia
- Inadequate assessment of needs including reviews and updates
- Lack of detailed care plans including choices and preferences and complex care needs
- Lack of coordination of visits requiring two care workers
- Lack of involvement of family or carers
- Failures to report safeguarding concerns in line with local policy, out-of-date procedures and staff not understanding safeguarding or whistleblowing procedures
- Staff feeling unsupported by their management teams and not always being able to deliver care in the right way because they are too rushed, with no travel time and unscheduled visits added to their day
- A lack of planned supervision and performance monitoring for staff
- Training needs not being identified, or if they are identified, they are not met
- Staff not being confident in using equipment
- Induction not always being completed, or not following recognised standards, and
- A lack of formal, documented quality monitoring processes within agencies.

The review began in April 2012 and ran alongside the regular programme of CQC inspections. It looked at whether people receiving care at home are treated with dignity and respect, are supported by staff, have choice about their care and benefit

from processes that are meant to keep them safe. During the review, the CQC inspected 250 services providing care to 26,419 people. This review found that good care involved input from people and their families, and involving them in decisions around their care. Another aspect of good care came from care staff who had gained knowledge of people's own routines and limitations. This allowed them to give people their independence to get on with their daily tasks without interfering until necessary. Good care involved channels for reporting complaints and abuse, and mechanisms for following up on these.<sup>(148)</sup>

## **NICE and the CQC**

NICE and the CQC work closely together but have very different remits. The CQC inspects health and care services to make sure that they provide good care that is safe, effective, caring, responsive, and well led, while NICE uses evidence to develop guidelines and quality standards on what good care looks like. The CQC also uses NICE guidelines as evidence in the inspection process and NICE quality standards inform CQC ratings of 'good' and 'outstanding'.<sup>(149)</sup> NICE prepares costing statements for the CQC to help with implementation of their standards and guidelines.<sup>(125)</sup>

### **3.4.10 Standards, guidance, policies and frameworks**

This section outlines the standards, guidance, policies and frameworks that are in place to support and monitor the quality of home support services in England.

#### **3.4.10.1 Standards**

This section outlines the standards that are in place in England with respect to home support services. It should be noted that Standards are not incorporated in the health and social care inspection methodology.<sup>(148)</sup> Instead, the CQC inspect against the regulations.

#### **Standards in legislation**

The Health and Social Care Act 2008 (Regulated Activities) Regulations 2014<sup>(57)</sup> provide for 'fundamental standards' for all of the activities regulated by the CQC. These are intended to apply across the whole range of regulated activities. The headings of the fundamental standards are as follows:

- General
- Person-centred care
- Dignity and respect
- Need for consent
- Safe care and treatment
- Safeguarding service users from abuse and improper treatment

- Meeting nutritional and hydration needs
- Premises and equipment
- Receiving and acting on complaints
- Good governance
- Staffing
- Fit and proper persons employed
- Duty of candour
- Requirement as to display of performance assessments.

The CQC adopts a human rights approach when regulating against these standards and outlines that everybody has the right to expect these fundamental standards and care must never fall below these standards.<sup>(146)</sup> The CQC has developed guidance for providers on meeting these standards and key lines of enquiry that guide its inspection against them.<sup>(126, 127)</sup> In line with the Care Act 2014, these key lines of enquiry have a strong emphasis on service providers being responsive and meeting people's day-to-day health and wellbeing needs.

## **NICE Standards**

In England, the independent standard-setting organisation NICE develop quality standards and performance metrics for those providing and commissioning health, public health and social care services.<sup>(125)</sup> NICE standards are not strictly enforceable and there is no legal requirement for health and social care services to adhere to national standards, however they are intended to be used to plan and deliver high-quality care and support in health and social care services. Relevant quality standards that have been produced by NICE are:

- Home care for older people<sup>(11)</sup>
- People's experience using adult social care services.<sup>(150)</sup>

## **Home care for older people (QS123 2016)**

In 2016 NICE published the quality standard QS123 'Home care for older people.' This quality standard applies in England and Wales, and specifically covers care and support for older people living in their own homes (described in the standard as homecare).<sup>(11)</sup> It covers people aged over 65 using homecare services, and may also cover some people under 65 with complex needs. It also describes high-quality care in priority areas for improvement. However, it does not cover intermediate (sub-acute) care, short-term re-ablement, or younger adults and children using homecare services. The NICE quality standard is endorsed by the Department of Health and Social Care, as is required by the Health and Social Care Act 2012.<sup>(143)</sup>

There are six quality statements in this standard. These are:

1. **Person-centred planning:** Older people using homecare services have a homecare plan that identifies how their personal priorities and outcomes will be met.
2. **Plan for missed or late visits:** Older people using homecare services have a homecare plan that identifies how their homecare provider will respond to missed or late visits.
3. **Consistent team of homecare workers:** Older people using homecare services receive care from a consistent team of homecare workers who are familiar with their needs.
4. **Length of homecare visits:** Older people using homecare services have visits of at least 30 minutes, except when short visits for specific tasks or checks have been agreed as part of a wider package of support.
5. **Reviewing the outcomes of the homecare plan:** Older people using homecare services have a review of the outcomes of their homecare plan within six weeks of starting to use the service and then at least annually.
6. **Supervision of homecare workers:** Homecare providers have practice-based supervision discussions with homecare workers at least every three months.

NICE also published a quick guide for people arranging their own homecare services, alongside this quality standard.<sup>(10)</sup>

### **People's experience using adult social care services (QS182 2019)**

This quality standard covers the experience of adults using social care services in England and Wales.<sup>(150)</sup> It applies to all settings where people use social care services, including people's own homes. Its aim is to help people understand what care they can expect and to improve their experience by supporting them to make decisions about their care.

There are four quality statements in this standard. These are:

1. **Care and support needs assessment:** People's personal strengths, preferences, aspirations and needs are discussed when they have a care and support needs assessment.
2. **Empowering people to manage their personal budget:** People using adult social care services have as much control as they would like over their personal budget.
3. **Continuity of care and support:** People using adult social care services have continuity of care and support.
4. **Using people's views to improve services:** People using adult social care services have their views used to inform service improvement.

### **3.4.10.2 Guidance, policies and frameworks**

This section describes the guidance, policies and frameworks that are in place in England to support the home support services sector.

#### **Better Use of Care at Home – NHS England**

NHS England have produced a series of online guides to support various health and care systems, including the quick guide 'Better Use of Care at Home.'<sup>(151)</sup> This guide contains links and resources, aimed at informing the home support services provider and staff. It focuses on three aspects of care delivered in the home:

1. planning for discharge home, on arrival at hospital
2. enabling people to go home with appropriate support, and
3. helping people to stay at home.

This quick guide also sets realistic expectations for what good home support services should achieve, and highlights that homecare cannot create immediate capacity without significant workforce planning.<sup>(151)</sup>

#### **The Handbook for Homecare Services in England - The Royal Pharmaceutical Society**

The Royal Pharmaceutical Society (RPS) published the Handbook for Homecare Services in England in 2014.<sup>(152)</sup> This was produced following recommendations from the 2011 report 'Homecare medicines: A vision towards the future' which was commissioned by the Department of Health.<sup>(153)</sup> The handbook contains overarching professional standards which provide a framework for service providers and commissioners to continuously improve home support services and medication safety. The handbook and these standards aim to help patients experience a consistent quality of homecare services, irrespective of homecare provider, that will support service-users to receive the best outcomes from their medicines. Each section of the Handbook for Homecare Services in England contains information and guidance and signposts and identifies key documents that will help home support service-providers manage their services within a clinical and financial governance framework.<sup>(152)</sup>

There are ten high-level professional standards, and these are grouped into three domains.<sup>(152)</sup> The handbook identifies currently available resources and good practice examples, which may be used by home support service-providers to improve their compliance with the three domains of the professional standards. The three domains are:

1. The patient experience

2. Implementation and delivery of safe and effective homecare services, and
3. Governance of homecare services.

The professional standards were developed by a government-commissioned Homecare Standards workgroup, overseen by the Department of Health Homecare Strategy Board, and hosted and published by the RPS.<sup>(152)</sup>

### **Homecare: Delivering personal care and practical support to older people living in their own homes - NICE**

As mentioned previously, NICE have published quality standards for home support services in England.<sup>(11)</sup> In 2015 NICE also published the guideline 'Homecare delivering personal care and practical support to older people living in their own homes,' which contained seven recommendations for improving home support services.<sup>(154)</sup> These recommendations are:

- ensuring care is person centred
- providing information about care and support options
- planning and reviewing homecare and support
- delivering homecare
- joint working between health and social care
- ensuring safety and safeguarding people using homecare services
- recruiting, training and supporting homecare workers.

The guideline was published alongside a guide for people receiving care and support in their home, outlining what they should be able to expect from services when the guideline was being adhered to.<sup>(145)</sup>

To help support implementation of their standards and guidelines, NICE published a flowchart overview for providers and local authorities in November 2020 on how to support home support services, which outlines how they should work at various levels of governance across an organisation to support high quality care that is personcentred and safe. The user can click on each stage in this flowchart to find details on how this step should be achieved. The flowchart summarises all of the points outlined in their home support quality standards and guidance and puts these in order of sequence of how they should be carried out.<sup>(154)</sup>

### **Getting help in your day-to-day life - Independent Age**

Independent Age, an advocacy group for older people, provide information on accessing adult social services through a step-by-step guide, called 'Getting help in your day-to-day life.' This guide outlines the needs assessment process in an interactive slide-show format, with plain English and cartoon illustrations to guide

the reader.<sup>(155)</sup> The guide focuses on understanding jargon, and offers multiple choice options depending on what the person accessing the guide is looking for.

### **3.4.11 Findings from reviews**

This section outlines findings from reviews of the delivery of home support services in England.

#### **3.4.11.1 Not just a number: Home care inspection programme - CQC**

From 2012-2013, the CQC carried out a review of home support services in England, which looked at whether people receiving care at home were being treated with dignity and respect, were supported by skilled staff, had choice about their care and benefited from processes that are meant to keep them safe. During the review, the CQC inspected 250 services providing care to 26,419 people, and found that there was pressure on services due to the arrangements for commissioning homecare, strains on social care budgets and the rise in the number of people with complex needs. The findings from this review were published on the CQC website in a report entitled 'Not just a number: Home care inspection programme.'<sup>(148)</sup>

#### **3.4.11.2 Report on adult social care statistics in England – The O**

The Office for Statistics Regulation (OSR) carried out a review of adult social care statistics in 2019, and the findings from this review were published online in January 2020.<sup>(156)</sup> This review found that there were significant gaps in what adult social care data currently measures, in particular the delivery of social care outside of statutory control, for example informal care. The review also found that there is little information on pathways and transitions between health care and social care, and recommended that new infrastructure is required to effectively address this. Finally the review also found little information on the quality of care and outcomes for those who experience social care.<sup>(156)</sup>

#### **3.4.11.3 Commissioning home care for older people – SCIE**

The Social Care Institute for Excellence (SCIE) is an independent improvement agency operating in England and funded by the government. The SCIE contributes to the development and implementation of better care, support and safeguarding at national and local level by offering consultancy, training, evaluation and research to complement government-funded commissions. SCIE also support commissioners and providers in developing and embedding practices which are innovative, have impact, and enable effective scrutiny and accountability.

According to this report by the SCIE, homecare services in England can be experienced as impersonal, inflexible, underfunded and poorly integrated with other

health and social care services. Services were found not to be designed around the person, but depended on how organisations are structured or who is doing the commissioning.<sup>(134)</sup>

#### **3.4.11.4 Report on roundtable discussion - NICE**

NICE carry out reviews of their standards and guidance in order to support their implementation. In 2016 they published the findings of a roundtable discussion on improving home support services in England through implementation of the 2015 NICE guideline 'Homecare: delivering personal care and practical support to older people living in their own homes'. The discussion focused on implementation of the guideline, framed around the following two questions:

- What are the three most important recommendations in the guideline?
- What can be implemented now?

In this discussion, participants noted that homecare work needs to be more highly valued by society, both financially and professionally, and the recruitment and retention of high-quality care staff needs to improve. They also noted that services need to have a greater knowledge of community resources, such as local volunteer groups, and to work more closely with them. The report also highlighted the roles of providers, home support staff, local authorities and regulatory bodies in working together to achieve implementation of the guideline. The nature of these working relationships can vary enormously, and trust and collaboration needs to be emphasised if positive change is to occur.

#### **3.4.11.5 Key to Care: Report of the Burstow Commission on the Future of the Home Care Workforce**

This 2014 report published by the Local Government Information Unit (LGIU), which supports local authorities, outlined recommendations on creating a professional, well-paid, well-trained and properly regulated workforce who can provide the quality of care at home that people need.<sup>(157)</sup> The report recognised the complex nature of social care and the inter-relatedness of problems and solutions. It features the stories of care workers, in their own words, who speak on both what needs to change and what could be the future of care. For example:

“In too many cases the domiciliary care market is failing to deliver positive outcomes for those receiving services, putting businesses and charities operating in the sector at risk of collapse and exploiting those who deliver care. The vast majority of care workers are extremely dedicated and hardworking individuals that are providing good quality care in spite of the system. While individual care companies can and are making improvements to the terms and conditions faced by care workers, the root of the problem is

systemic and can only be tackled with the buy-in of commissioners. The continued predominance of task and time commissioning has created a race to the bottom and has institutionalised an attitude where care workers are seen as overheads. For the sake of the England's 685,000 care workers it is time to act."<sup>(157)</sup>

The report found also that the home support services workforce in England is not well organised, and prevents caring professional relationships from forming between workers and those they care for.

#### **3.4.11.6 Reviews by the King's Fund (2016-2018)**

The King's Fund has carried out multiple reviews on homecare in England. Between 2016 and 2018, the King's Fund carried out three pieces of research exploring the factors driving the commissioning of adult social care, the mechanisms of purchasing and delivery of homecare, and alternatives to traditional models of delivering care at home. The 2018 report 'Home care in England: views from commissioners and providers' draws together the findings of those research projects, which recorded the stated opinions of commissioners, providers and other stakeholders, and identified major issues in recruitment and workforce retention. This report was published following on from the 2018 'New models of home care' which explored new approaches to homecare commissioning and delivery, and considered their potential to provide care that is more closely aligned with what people want.<sup>(87)</sup>

'New models of home care' looked at models such as 'Shared Lives', in which individuals are supported in a paid carer's home, and others such as local area co-ordination, which aim to harness a person's own resources and those of their family and community to support them more effectively. While these models reported very strong outcomes, they were not new and there were doubts about the extent to which they were fully scalable or could fully replace traditional homecare services.<sup>(87)</sup>

#### **3.4.11.7 State of Care – Annual CQC assessment of healthcare and social care**

This report, published by the CQC in November 2021, outlines the trends and factors impacting on health and social care delivery in England between the years 2020-2021, and highlights where services have exceeded or not met quality expectations.<sup>(158)</sup> The report focuses largely on how services were impacted by the COVID-19 pandemic, and addresses the 'intensely damaging' effects on people who have not been able to get the care that they need, and those who have delayed seeking access to care and support. The report states that the pandemic exacerbated already existing issues, such as staff shortages and issues in retention and recruitment, burnout, and loss of motivation. As per data from this report, an

additional 4.5 million people have become unpaid carers since the beginning of 2020, and this has resulted in additional strain and pressure on the sector. Despite these issues, people using care and support services report a positive experience of services once they have access to them.<sup>(158)</sup>

### **3.4.11.8 Build Back Better: Our Plan for Health and Social Care**

In September 2021, the Government published a new strategic plan for reform of health and social care to address issues caused and highlighted by the COVID-19 pandemic. This plan seeks to address waiting lists for health and social care services, keep people cared for in their own homes where this is possible, and invest in the NHS to address issues caused by delayed access to services. The plan also introduced lifetime caps on how much a person can be charged for their personal care, which are outlined in section 3.4.6.<sup>(141)</sup>

### **3.4.11.9 Health and social care integration: joining up care for people, places and populations**

In February 2022, the Government of England published a white paper outlining measures for integration of health and social care.<sup>(159)</sup> This white paper was published on the back of planned reforms outlined in the Build Back Better strategy, and is aimed at joining up care for:

- Patients and service users
- staff looking for ways to better support increasing numbers of people with care needs, and
- organisations delivering these services to the local population.

The white paper emphasises the importance of keeping people cared for in their own homes where this is possible, and illustrates case studies of people receiving homecare and support services.<sup>(159)</sup> The paper highlights the importance of integration of services, particularly in the context of people receiving care and support in their own homes, and outlines the importance of 'shared outcomes' for health and social care organisations.<sup>(159)</sup>

### **3.4.12 Summary and lessons for Ireland**

Home support services in England are provided to older people, people with conditions that limit their ability to live independently at home, and people with disabilities, if these people are determined to need these services based on a care needs assessment. As home support services in England are financially means tested, only those who cannot afford to pay for their care will receive care free of charge from their local authority. In the majority of cases, people will have to pay

for their care and support at least in part, and there is a heavy reliance on the private sector.

Irish home support services are not currently regulated in legislation. Home support services in England however are regulated through the Care Act 2014 and the Health and Social Care Act 2008. Embedding similar legislation in Ireland will strengthen the regulation of home support services and provide legal footing for the sector.

In England, home support services are provided to adults who need them. However, the term 'adult' is not defined. The age of people receiving care and support can be a grey area, as the CQC technically only look at adults (over 18), but some domiciliary care agencies would cater to children or younger people. It may be important to consider that having defined age limits for access to home support services could present with barriers or gaps in accessing care and support.

It is important that all potential recipients of homecare can be assessed using the same criteria, therefore there is a need in Ireland to establish a standardised means for assessing eligibility for care and support. In England, the Care Act 2014 established a national minimum eligibility for care and support, and outlined criteria for eligibility in legislation. Having such a process for assessing care and support needs, a two-step process with financial eligibility separated from eligibility based on care needs, may improve the consistency of how home support services are delivered in Ireland. However, in England there is no established timeline within which care needs assessments should take place. Despite this, care and support can be delivered to those who urgently require it on an emergency basis, which may relieve the pressure on people who would otherwise be subject to waiting times or potential gaps in their care and support. As a result, home support services can occasionally be allocated to those with the highest or most complex, acute care and support needs.

Currently, there are no national standards in place for home support services in Ireland. In England, while the Care Act 2014 outlines fundamental standards against which health and social care services should be regulated, these are the only legally enforceable standards and are not specific to home support services. NICE standards provide home support service providers and the CQC with benchmarks and goals for what good home support services should look like, however there is no legal requirement for these to be adhered to. However, there are no reviews or evaluations of these standards in practice and therefore it is unclear what lessons, if any, can be learned from these standards.

Household tasks are not included in the scope of personal and nursing care provided to people in their homes in England, and are not regulated by the CQC. Excluding household tasks may cause difficulty in gathering a holistic view of the quality of

care and support being delivered by a home support services agency during inspections, and may not fully support the wellbeing and quality of life of the person.

Numerous reports and reviews of home support services in England highlighted issues with recruitment and retention of staff, working conditions for staff, and how the workforce is regulated. In England, there is no registration requirement for individual domiciliary care workers, nor is there any requirement for staff to be fully qualified before they begin working. This is evidenced by the fact that up to two thirds of domiciliary care staff have not fully completed the Care Certificate, which is expected to be completed by all paid carers.<sup>(159)</sup> There is some potential learning for Ireland from the English home support services workforce, whereby registration and qualification requirements should be highlighted and pre-requisites should be clarified.

## **3.5 Northern Ireland**

### **3.5.1 Overview of home support services**

In Northern Ireland, home support services are mainly referred to as 'domiciliary care' services and fall under social care, with the Department of Health having overall responsibility for domiciliary care delivery. In addition, Northern Ireland legislation places a duty on the Department of Health to set national health and social care standards. In 2011, the formerly-known Department of Health, Social Services and Public Safety (DHSSPS) developed and published a set of minimum care standards for domiciliary care services in Northern Ireland. The standards form an integral part of regulating, inspecting and monitoring domiciliary care services. An emerging area in social care is an ageing population with complex needs and a drive to keep people out of hospital and living as independently as possible in their own homes for as long as possible. This is evident in Northern Ireland where government bodies have commissioned reviews seeking subject matter expert advice and recommendations on enhancing the delivery of home support services across Northern Ireland. This section of the review provides a summary of how home support is delivered in Northern Ireland. It sets out its governance structures, key organisations involved in home support and key pieces of Northern Ireland's legislation that relate to home support services. This section is set out under the following headings:

- Model of home support service delivery
- Relevant legislation and regulation
- Standards, guidance, policies and frameworks and implementation
- Findings from reviews
- Summary and lessons learned.

### **3.5.2 The model of Home Support care service delivery**

This section describes the landscape of home support across Northern Ireland and is set out under the following sub-headings:

- Structure and governance
- Scope
- Eligibility and assessment of need
- Funding and commissioning
- Workforce.

### 3.5.3 Structure and governance of home support services

Home support services are referred to as 'domiciliary care' or 'homecare services' in Northern Ireland. These services are provided through adult social care services, which is part of the health and social care system in Northern Ireland.<sup>(160)</sup> Health and social care is publicly funded and the Department of Health sets the policy and legislative context for health and social care, with overall responsibility for health and social care services in Northern Ireland.

The Department of Health discharges duties on commissioning and provision of services to the Health and Social Care Board (HSCB) who works in partnership with the Public Health Agency (PHA) in managing a full range of health and social care services. The Board is responsible for commissioning services, resource and performance management and service improvements. It operates across six Health and Social Care Trusts, five of which provide integrated health and social care services to the public in Northern Ireland and thus, includes domiciliary care services. The five trusts are:

- Belfast Health and Social Care (HSC) Trust
- Northern Health and Social Care (HSC) Trust
- South Eastern Health and Social Care (HSC) Trust
- Southern Health and Social Care (HSC) Trust
- Western Health and Social Care (HSC) Trust.

Each trust is responsible for managing its own staff and services and controls its own budget, with the aim of improving the health and social wellbeing of people using services, and reducing health inequalities in the provision of health and social care.

Domiciliary care services are provided by independent or statutory providers and operate conjointly with supported accommodation services.<sup>(160)</sup> Statutory providers are those that are paid for and provided by the HSC Trusts. Supported accommodation in Northern Ireland provides extra housing support and if required, care and support to help a person live an independent life as much as possible. Where services are accredited as a housing support service which also provides personal care, this service is required to register as a domiciliary care agency in Northern Ireland.<sup>(161)</sup>

An annual survey carried out by the Department of Health in Northern Ireland in 2019 reported that HSC Trusts directly provided or commissioned domiciliary care

services for 23,425 clients in 2019, with 29% provided by the statutory sector and 71% by the independent sector.<sup>(162)</sup>

The Regulation and Quality Improvement Authority (RQIA) is the independent health and social care regulatory body for Northern Ireland. RQIA registers and inspects independent and statutory health and social care services including domiciliary care services. There is also compulsory registration for all social care workers including domiciliary care workers with the Northern Ireland Social Care Council (NISCC) which was introduced in September 2015.

### **3.5.4 Scope of home support services**

As previously stated, homecare services in Northern Ireland are referred to as 'domiciliary care' or 'homecare.' South Eastern and Northern HSC trusts use the term 'domiciliary care'. Belfast and Western HSC trusts use the term 'homecare'. The Southern HSC trust use 'Domiciliary Care or Home help' to describe homecare support. The Department of Health places an emphasis on domiciliary care being that of rehabilitation and enabling people to support their independence, maintain existing abilities and develop new skills. Differences exist in how domiciliary care is defined among government bodies in Northern Ireland. This variation was highlighted in a report by the HSCB that identified a lack of a standardised definition and interpretation of what is meant by domiciliary care and hence, analysing activity across the trusts in this area was difficult.<sup>(163)</sup> The most widely-used definition is from the Department of Health:

Domiciliary care is the range of services put in place to support an individual in their own home. Services may involve routine household tasks within or outside the home, personal care of the client and other associated domestic services necessary to maintain an individual in an acceptable level of health, hygiene, dignity, safety and ease in their home.<sup>(39)</sup>

Domiciliary care services provide home-based support for older people or those with disabilities who wish to remain living in their own homes for as long as they are able to do so. Domiciliary or homecare services are defined as the range of services put in place to support a person in their own home.<sup>(164)</sup> These services cover personal care, practical care, non-residential respite care, day care or resource centres, and transport as required.<sup>(165)</sup> They can be an overnight, live-in or a 24-hour service. Disability in Northern Ireland is described as

Disability is a physical or mental impairment which has a substantial and long-term adverse effect on a person's ability to carry out normal day-to-day activities.<sup>(166)</sup>

A survey carried out during a sample week in 2019 found that 84% of people using domiciliary care services in Northern Ireland were aged 65 years or over and 16% were aged 18-64 years old.<sup>(162)</sup> This survey grouped the people using domiciliary care services according to their needs and reported that 80% were in the older person group, 11% had a physical disability, 5% had a learning disability and 4% had mental health needs.<sup>(162)</sup>

The Department of Health updated guidance in 2015, entitled *Home help and Domiciliary care guidance – Documents Circular HSS (SS) 1/80* that sets out a list of duties appropriate to domiciliary care in the context of home help and personal and social tasks. This circular identifies the scope of a domiciliary care service as a home help service that will be provided by the HSC Boards as requested and considered appropriate to the needs of the person. The duties applicable to home help listed in this circular are as follows:

- Household tasks:
  - undertaking routine or regular household cleaning
  - preparing and cooking food
  - washing up
  - lighting fire and bringing in fuel
  - making beds
  - washing and ironing personal clothing
  - arranging for the laundering of bed linens and towels
  - shopping – including errands such as collecting pension and or prescriptions, posting letters, paying rent and other accounts
  - emptying commode.
  
- Personal and social care tasks:
  - caring for children
  - helping with washing and bathing
  - helping with dressing and undressing
  - helping with shaving and hairdressing
  - helping with personal hygiene and toileting
  - contacting GP (for example, facilitating contact with GP by use of telephone to make appointments)
  - supervising medicines
  - encouraging the use of aids provided

- encouraging the continuation with any exercises prescribed
- encouraging the continuation with any medication or treatment
- encouraging contact with relatives
- encouraging the continuation with any hobby or social activity.

Personal care is defined by the Department of Health as:

'Personal Care is undertaking any activity which requires a degree of close personal and physical contact with individuals who regardless of age, for reasons associated with disability, frailty, illness, mental health or personal physical capacity are unable to provide for themselves without assistance'.<sup>(165)</sup>

In addition, HSC trusts provide 'intensive' homecare that enables older people and people with disabilities to remain in their own homes for as long as possible. Intensive homecare is defined as six or more visits and more than 10 contact hours per week.<sup>(39, 162)</sup> This service is mostly used for people aged 65 years and over who have a range of health and social care needs and may require the assistance of two staff members at all times. This is an example of how the definition of domiciliary care has expanded across some trusts to include complex tasks such as assistance with medicines, stoma and catheter care.

The Department of Health guidance circular also included guidelines for the allocation of time deemed reasonable to complete an activity.<sup>(165)</sup> Examples of activities and allocated times provided in the guidelines by the Department of Health are presented in table 3.3. During a sample week in 2019, a national survey reported that 31% of homecare visits were 15 minutes or less, 54% were 15-30 minutes and 15% were over 30 minutes.<sup>(162)</sup>

**Table 3.3: Allocation of hours based on task times for a person receiving home help**

Task/ Activity	Daily Time	Weekly Allowance
Preparing cooking, serving meals	0 to 60 minutes	Up to 7 hours
Making bed	0 to 5 minutes	Up to 35 minutes
Helping with dressing	0 to 30 minutes	Up to 3 hours 30 minutes
Helping with undressing	0 to 15 minutes	Up to 1 hour 45 minutes
Shopping or errands or contacting GP	0 to 10 minutes	Up to 1 hour
Helping with washing, shaving, personal hygiene and toileting	0 to 30 minutes	Up to 3 hours 30 minutes (includes time allowance for weekly bath and hair washing).
Social Support	0 to 60 minutes	Up to 6 hours

**Source:** NI Department of Health (2015). Home help and Domiciliary care guidance – Documents Circular HSS (SS) 1/80.<sup>(167)</sup>

### 3.5.5 Eligibility and assessment of need

A key principle underpinning the approach to eligibility and fair access to domiciliary care in Northern Ireland is that people are helped wherever possible “to live independent lives with safety and dignity in their homes”.<sup>(167)</sup> Eligibility for domiciliary care is determined by the assessment of need and if the HSC trusts can provide help in relation to those needs identified. It is based on four assessed levels of need: critical, substantial, moderate and low. A person will receive appropriate domiciliary care services if their risk assessment identifies a critical or substantial risk to independence and help cannot be sourced from elsewhere, for example family carers.<sup>(167)</sup> Risk assessments evaluate a person’s autonomy, health and safety, ability to manage day-to-day living and involvement of family in their care. Domiciliary care packages are also dependent on existing availability of hours and service packages that the Trust can provide.<sup>(160)</sup>

Every person with a presenting issue or need that can be addressed by a care service is entitled to an assessment and all Trusts have a duty to provide an

assessment to those that need help.<sup>(167)</sup> An assessment of needs and the development of a care plan is provided by a HSC Trust or contracted by the HSC Trust to an independent provider to deliver.<sup>(168)</sup>

The Northern Ireland Single Assessment Tool (NISAT) is used to assess an older person's support needs across a range of services and also to evaluate risks applicable to the person's needs and independence. It forms part of the Older People's Programme of Care in Northern Ireland.<sup>(164)</sup> The NISAT is a single standardised assessment tool, developed for older people and consists of four key components<sup>(169)</sup>; initial assessment or short term intervention, core assessment, complex assessment, and consent. Additional forms included in the NISAT are: specialist assessment summary; referral information; medical practitioner report; assessor analysis, summary and action details; carers support and needs assessment.

The NISAT encompasses a person-centred, holistic framework that was developed by the University of Ulster, as commissioned by the formerly-known Department of Health, Social Services and Public Safety (DHSSPS) to capture the multiple health and social care needs of an individual and also the multiple assessments carried out by many health and social care professionals.<sup>(68)</sup> NISAT seeks to standardise and improve assessment practice within health and social care, with a view to ensuring that individuals and their carers receive services which are responsive and appropriate to their needs. It places a requirement on health and social care practitioners to work collaboratively and more effectively across services and professional roles.<sup>(24)</sup> Responsibility for undertaking the initial assessment using the NISAT rests with the key person involved in the person's care and must be a social worker or health professional.

The Department of Health in Northern Ireland reported that the NISAT aims to take into account patient and carers perspectives, thus enabling a partnership approach and effective collaborations and decision-making with the multi-disciplinary team.<sup>(169)</sup> In addition, the NISAT evaluates support from carers. Carers have a statutory right in Northern Ireland to have an assessment of their role and needs.<sup>(167)</sup> Carers may include family members or friends and, if a carer can provide assistance with a care need for the person, then this is not considered an eligible need. The Department of Health provides all the components that make up the NISAT on their website in easily accessible word documents.<sup>(169)</sup>

A review of the implementation of the NISAT was commissioned by the DHSSPS in 2011. This review was initially planned in four stages but it was later agreed that the Department of Health no longer required all four stages and hence, two stages were

completed by RQIA. The first review examined the care management practice, process and assessment tools in place for older people across the five HSC Trusts prior to the implementation of NISAT. The second review examined the use of the carer's support and needs assessment component of NISAT.

### 3.5.6 Funding and commissioning

Domiciliary care services are provided free of charge to people aged 75 years and over in Northern Ireland, and to people in receipt of income support or family income supports, within an annual budget for the service and in accordance with eligibility criteria. Direct payment schemes were introduced under the Carers and Direct Payments Act (Northern Ireland) 2002 which authorises direct payments to be available to people who are assessed as needing domiciliary care services, thereby, allowing the person to manage their own payments for social care provision and promoting independence. The functions in relation to direct payments have been delegated to HSC Boards and Trusts. The overall aim is that Boards and Trusts would offer as much as possible to the individual, in allowing the individual to address their own needs and that public funds are being spent appropriately and with best value. There is an obligation on Boards and Trusts to satisfy themselves that the scheme they develop serves all potential direct payment recipients equitably. In addition, they must ensure information about direct payments is readily available to people and should be included in Board and Trust community care plans.<sup>(170)</sup>

Qualitative findings from a study published in 2019 that examined the views, opinions and expectations of social care from older people living in Northern Ireland found that the majority of participants at three focus groups were not aware of the direct payment scheme. When the researcher explained this scheme to the participants, the majority were opposed to the direct payments. Reasons for this included that the system is too complex and will require additional responsibilities from people using services. The researcher concluded that the lack of enthusiasm could be due to limited information, advice and support accessible to people.<sup>(171)</sup>

The HSCB is responsible for commissioning domiciliary care services and have local commissioning groups that are associated with each HSC trust. It is these groups that are responsible for the assessment of need and planning health and social care to meet the needs for the local population. The assessment of need informs the delivery of care services, their procurement, be it independent or statutory, and the monitoring of those services. However, the commissioning of domiciliary care in Northern Ireland has been criticised for having high levels of inconsistencies in planning and delivery of services. In addition, HSCB and Trusts adopt a time and

task approach to commissioning domiciliary care, as opposed to an outcome-based approach.

### 3.5.7 Workforce

The legislation that governs domiciliary care in Northern Ireland, The Health and Personal Social Services, The Domiciliary Care Agencies Regulations (Northern Ireland) 2007, describes a domiciliary care worker as a person who:

- is employed by an agency to act for, and under the control of, another person
- is introduced by an agency to a service user for employment by him
- is employed by a direct service provider
- in a position which is concerned with the provision of prescribed services in their own homes for persons who by reason of illness, infirmity, disability or family circumstances are unable to provide any such service for themselves without assistance.<sup>(172)</sup>

A rapid learning review of domiciliary care in Northern Ireland conducted by the Department of Health in 2020 reported that there are 16,206 registered domiciliary care workers, 531 registered domiciliary care managers, 2,073 registered supported living workers, and 120 domiciliary care providers in Northern Ireland.<sup>(39)</sup>

There is compulsory registration for all social care workers including domiciliary care workers with the Northern Ireland Social Care Council (NISCC), which was introduced in September 2015.<sup>(160)</sup> The NISCC is the regulatory body for the social care workforce in Northern Ireland. It is a non-departmental public body and is sponsored by the Department of Health and was established under the Health and Personal Social Services Act (Northern Ireland) 2001. Its aim is to increase the protection of those using social care services, their carers and the public.

Registered social care workers are required to comply with the NISCC Standards of Conduct and Practice for social care workers at all times. This was seen as an important step forward in the development of the domiciliary care workforce, establishing the foundations for standards of practice including values, attitudes and behaviours, as well as focusing on the knowledge and skills required to achieve competency. The NISCC have developed and published a set of standards for social care workers to comply with, *Northern Ireland Social Care Council Standards of Conduct and Practice for Social Care Workers*.<sup>(173)</sup> They consist of two sets of standards:

- Standards of conduct that describe the values, attitudes and behaviours expected of social care workers in their day to day work.
- Standards of practice that outline the knowledge and skills required for competent practice.

These sets of standards provide a baseline against which a social care worker's conduct and practice are judged.<sup>(173)</sup> Fitness to practise is measured against these standards and failure to comply with them can put a person's registration at risk. In addition, the standards are intended to assist service users and carers by protecting and promoting their interests and wellbeing. The following values inform and underpin the standards of conduct and practice. Social care workers must:

- respect the rights, dignity and inherent worth of individuals
- work in a person-centred way
- treat people respectfully and with compassion
- support and promote the independence and autonomy of service users
- act in the best interests of service users and carers
- uphold and promote equality, diversity and inclusion
- ensure the care they provide is safe and effective and of a high quality.

The Commissioner for Older People in Northern Ireland published a review of domiciliary care in Northern Ireland in 2015 and recommended the introduction of a qualification framework, with a clear pathway for career progression for domiciliary care workers.<sup>(160)</sup> In addition, training domiciliary care staff to the level required to provide safe and effective care was recommended. Following on from this, the NISCC published guidelines, *Workforce Development and Qualification Guide*, to assist employers and social care staff on qualifications that are essential, desirable or relevant to developing the required knowledge and skills to ensure support and care is provided at the highest standard.<sup>(174)</sup> These guidelines place an emphasis on Continuous Professional Development (CPD) and provide a guide on qualifications for social care staff. However, they also delegate responsibility onto employers across services to set their own qualification requirements based on service need. Table 3.4 displays the descriptors provided in the NISCC guidelines for domiciliary care workers under job role and function, desirable current qualifications or training and CPD. In addition, Table 3.5 displays essential training, desirable qualifications and CPD qualifications for domiciliary or homecare workers.<sup>(174)</sup>

**Table 3.4: Descriptions of job roles and qualifications for domiciliary care workers**

Job Examples	Job Role and Function	Desirable Current Qualifications/Training and CPD
Domiciliary care assistant or homecare worker	Care and support  Assist with everyday living	Induction In house training CPD Level 2 Diploma in Health and Social care (Adults) Wales and Northern Ireland

**Source:** NISCC guidelines (2015). Workforce Development and Qualification Guide.<sup>(174)</sup>

**Table 3.5: Essential training, desirable qualifications and CPD qualifications for domiciliary or homecare workers**

Essential	Desirable Current Qualifications	CPD	Other/previous accepted qualifications
Induction training from their employer using NISCC Induction Standards within the first six months of commencing employment.  Post Registration Training and Learning (PRTL) - All registrants must complete 90 hours PRTL in each registration period. NISCC defines PRTL as the learning and	Certificate in Induction in Adult Social Care (Northern Ireland).  Level 2 Diploma in Health and Social Care (Adults) for Wales and Northern Ireland.	Health and Social Care Vocational Qualifications. For example safeguarding, dementia awareness, supporting people with learning disabilities.  Progression in CPD should be monitored by the use of a personal development plan.	National Vocational Qualification* (NVQ) 2  Health & Social Care NVQ 2

development activities through which you maintain and develop your competence.			
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\*competency-based qualifications

**Source:** NISCC guidelines (2015). Workforce Development and Qualification Guide.<sup>(174)</sup>

Registered managers in regulated services such as domiciliary care services are the only group of social care staff where there is currently a mandatory requirement for a qualification. This is detailed in the NISCC *Workforce Development and Qualification Guide*. Detailed qualification and experience requirements are also set out in the minimum standards document for domiciliary care services developed by the DPPSS<sup>(161)</sup> and form part of the services' registration requirements in accordance with articles 12 to 22 of The Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003.<sup>(172)</sup> The qualification requirements include having a social work or health professional qualification with associated registration and a set minimum years of experience working in a health and or social care setting which also incorporated working in a managerial capacity.

### **3.5.7.1 The Standards for Employers of Social Workers & Social Care Workers 2017**

Employers are expected to support and enable their registered workforce to meet the Standards of Conduct and Practice as set out by the NISCC.<sup>(175)</sup> The Standards comprise of five standard declarative statements that have indicators or features of how the employer can comply with the Standard. They are intended to complement existing employers' policies and contribute to the relevant legislation, requirements and guidance that relate to the employment of staff.<sup>(175)</sup>

### **3.5.8 Relevant legislation**

This section describes key legislation in Northern Ireland that applies to home support services. Northern Ireland has a range of legislation that places duties on government bodies, the regulator, domiciliary care agencies and registered managers.

### **3.5.8.1 The Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003**

The Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003 places a statutory obligation on each HSC Trust to have arrangements in place for monitoring and improving the quality of health and social care which it provides to individuals and the environment in which it provides them. This Order establishes the Northern Ireland Regulation and Quality Improvement Authority (RQIA) and makes provision for the registration and regulation of certain services such as domiciliary care agencies. It sets out the requirements of regulation relating to domiciliary care agencies and the role and duties of the regulator in a framework of quality, regulation and inspection. It gives authority to the regulator to require information from services to enter and inspect services. A statutory duty is placed on HSC Boards and Trusts to provide a quality service and meet a required standard. In addition, this legislation places a duty on the Department of Health to develop, publish and amend accordingly, statements of minimum standards applicable to regulated services. RQIA must take these standards into account in the regulation of services such as domiciliary care agencies.<sup>(172)</sup> This piece of legislation defines domiciliary care as:

'Domiciliary care is an undertaking which consists of or includes arranging the provision of prescribed services in their own homes for persons who by reason of illness, infirmity, disability or family circumstances are unable to provide any such service for themselves without assistance'.<sup>(172)</sup>

### **3.5.8.2 Health and Personal Social Services, The Domiciliary Care Agencies Regulations (Northern Ireland) 2007**

Domiciliary care agencies in Northern Ireland are regulated by RQIA under Health and Personal Social Services, Domiciliary Care Agencies Regulations (Northern Ireland) 2007. These Regulations are made under the Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003. Compliance with the regulations is mandatory and a breach of a regulation or regulations may be found as an offence on the part of the registered person. RQIA is obliged to inform the registered person in what respect the service is deemed as not complying with a regulation and what must be done in a given timeframe to comply with the regulation. The regulations refer to a domiciliary care agency providing prescribed services which are personal care and an assessment of the need of personal care. The regulations are set out in this Order and cover a wide range of service activity including:

- statement of purpose
- fitness of registered provider
- employment of staff
- fitness of the person managing the agency
- conduct of the agency with emphasis on need for appropriate training and the provision of a quality service
- fitness of domiciliary care workers
- conduct of agency where domiciliary care workers are supplied to persons by an agency acting as an employment agency
- staffing and staff handbook
- provision of information to service users
- disclosure of information
- record keeping
- complaints
- assessment, evaluation and improvement planning of the quality of services
- financial management of the agency
- notices to the Regulation and Improvement Authority.

### **3.5.8.3 The Health and Social Care (Reform) Act (Northern Ireland) 2009**

The Health and Social Care (Reform) Act (Northern Ireland) 2009 made changes to the structuring of administration of health and social care and the role of regional boards in promoting and providing health and social care in Northern Ireland. It also extended the functions of RQIA to mental health and learning disability services.<sup>(176)</sup>

### **3.5.8.4 Care Act 2014**

Sections 48 to 52 of the Care Act 2014 places duties on authorities in England, Wales and Northern Ireland to meet the needs of individuals in circumstances where registered providers of care are unable to carry on because of business failure.<sup>(129)</sup>

### **3.5.8.5 Carers and Direct Payments Act (Northern Ireland) 2002**

The Carers and Direct Payments Act (Northern Ireland) 2002 places a duty on HSC Trusts to inform carers of their legal right to a care assessment and to be considered for services to meet their own needs. The Act gives HSC Trusts the right to provide personal social services to support carers directly. HSC Trusts retain discretion to decide whether or not to provide a service to meet a need identified in a carer's assessment.<sup>(177)</sup>

### **3.5.8.6 Disabled Persons (Northern Ireland) Act 1989**

The Disabled Persons (Northern Ireland) Act 1989 sets out the arrangements for appointing an authorised representative, should it be required for a person with a disability. In addition, it sets out the rights of the authorised representative. The Act places a duty on government bodies, for example the HSCB and HSC Trusts, to have provisions in place for the assessment of need for a person with a disability and also to take into account the abilities of carers.<sup>(178)</sup>

### **3.5.8.7 Mental Health (Northern Ireland) Order 1986**

The Mental Health Order (Northern Ireland) 1986 makes provisions for appointing guardianship, should it be required for a person with a mental health condition. The order also sets out the assessment, care, treatment and rights of people with a mental health condition in Northern Ireland.<sup>(179)</sup>

## **3.5.9 Regulation**

This section describes the key organisation and its duties that governs the regulatory framework for home support services in Northern Ireland.

RQIA is the independent health and social care regulatory body for Northern Ireland. RQIA registers and inspects independent and statutory health and social care services including domiciliary care services. It is responsible for ensuring the quality of services and that domiciliary care providers meet the *Domiciliary Care Agencies Minimum Standards* published by the DHSSPS in 2011.<sup>(160, 180)</sup> RQIA must take into account the extent to which the minimum standards have been met in determining whether or not a service maintains registration or has its registration cancelled, or whether to take action for breach of regulations.<sup>(161)</sup> Compliance with the regulations is mandatory and non-compliance with some specific regulations is considered an offence. The regulations and minimum standards for domiciliary care agencies focus on ensuring that people using the services are protected and the provision of care is quality-assured.

Inspections conducted by RQIA are underpinned by The Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003, The Domiciliary Care Agencies Regulations (Northern Ireland) 2007, and The Domiciliary Care Agencies Minimum Standards (2011). In addition, inspections are conducted and reported under four domains:

1. Is care safe?
2. Is care effective?
3. Is care compassionate?
4. Is the service well led?

During inspections, RQIA look at evidence for policies, procedures and records, and will have discussions with people using the services, managers and staff. Domiciliary care services are inspected at least once every year and are usually unannounced inspections.<sup>(43)</sup> RQIA holds up-to-date information on all registered health and social care services in Northern Ireland including domiciliary care agencies. Their inspection reports are publicly available and aim to guide a person's decision when selecting an appropriate home support service. They have an online directory that allows people to search for such services by name, care category, geographical area, and postcode.

### **3.5.10 Standards, guidance, policies and frameworks**

This section will describe the minimum care Standards for the regulation, inspection and monitoring of home support services in Northern Ireland. In addition, guidance documents have been developed to support the implementation of the Standards will be discussed in section 4.2.

#### **3.5.10.1 The Domiciliary Care Agencies Minimum Standards**

The Domiciliary Care Agencies Minimum Standards (2011) were developed by the DHSSPS in accordance with article 38 of The Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003.<sup>(172)</sup> The Standards document sets out the absolute minimum standards and level of care required to support a person in their own home. The standards specify the arrangements and procedures that need to be in place and implemented to ensure the delivery of a quality service. They apply to:

- Domiciliary care agencies defined under The Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003. This includes both independent and statutory providers of such services.
- Supported accommodation services that provide personal care in addition to housing support services.
- Intentional communities where personal care is an aspect of service provision.

The standards are underpinned by the following values:

- Dignity and respect
- Independence
- Rights
- Equality and diversity
- Choice

- Consent
- Confidentiality
- Safety.

These values place an emphasis on listening to, valuing and upholding the human rights of people using domiciliary care services. They should be embedded in everyday practice including planning, delivery and review of services and aim to provide a friendly and caring service. The standards set out that a service underpinned by the values and meeting the minimum standards is one that delivers the best possible outcomes for people using the service.<sup>(161)</sup>

The standards comprise of 16 standard statements and are divided into two sections; Quality of Care, and Management of the Domiciliary Care Agency. The statements describe the process of care delivery, as opposed to being outcome-based. They have associated criteria that are designed to be measurable by means of self-assessment and inspection. The Quality of Care section centres on systems of assessment, care planning and review, using appropriate experienced and qualified staff members, whilst also meeting the needs of the person using the service. An emphasis is placed on the occurrence of home visits between the agency and the person using the service prior to commencing homecare. Social care workers are trained according to needs of the person using the service, for example, medicine management. The Management of the Domiciliary Care Agency section places a focus on policies and procedures, and staff recruitment, with an emphasis on the registered manager.<sup>(161)</sup> Table 3.6 presents each standard and standard statement.

**Table 3.6: The Domiciliary Care Agencies Minimum Standards (2011)**

<b>Quality of Care</b>		
	<b>Standard Title</b>	<b>Standard Statement</b>
Standard 1	Service users' involvement	The views of service users and their carers/representatives shape the quality of services provided by the agency.
Standard 2	Information for service users	Prospective service users are provided with information on the services provided by the agency.
Standard 3	Referral arrangements	Referral arrangements ensure the service user's identified needs can be met by the agency.
Standard 4	Agreement between a service user and the agency	Each service user has a written individual service agreement.
Standard 5	Recording and reporting	All activities undertaken in relation to the service user's care plan are recorded and relevant information communicated to the appropriate people.
Standard 6	Contributing to a service user's reviews	The agency contributes to the review of the service user's care plan.
Standard 7	Management of medicines	The agency has arrangements in place to ensure that care workers manage medicines safely and securely.
<b>Management of the Domiciliary Care Agency</b>		
Standard 8	Management and control of operations	Management systems and arrangements are in place that support and promote the delivery of quality care services.
Standard 9	Policies and procedures	There are policies and procedures in place that direct the quality of care and services.
Standard 10	Management of records	Clear, documented systems are in place for the management of records in accordance with legislative requirements.

Standard 11	Recruitment of staff	Staff are recruited and employed in accordance with relevant statutory employment legislation.
Standard 12	Staff training and development	Staff are trained for their roles and responsibilities.
Standard 13	Staff supervision and appraisal	Staff are supervised and their performance appraised to promote the delivery of quality care and services.
Standard 14	Protection of vulnerable adults and safeguarding children	Service users are protected from abuse.
Standard 15	Complaints	All complaints are taken seriously and dealt with promptly and effectively.
Standard 16	Safe and healthy working practices	The agency has systems that ensure safe and healthy working practices.

**Source:** NI Department of Health (2011). The Domiciliary Care Agencies Minimum Standards.<sup>(161)</sup>

In addition, the standards document provides the regulatory requirements according to legislation, essential qualifications necessary to be a registered manager and a comprehensive list of policies and procedures (65 in total) that are required to be in place in a domiciliary care service.

A report by the Commissioner for Older People for Northern Ireland published in 2015 recognised that the Quality of Care section of the Standards (standard 1-7) reflects the perspective of the person using the service. However, the Commissioner advised that standards should focus more on the person's experience of care. In addition, an essential component of inspections should encompass the user-experience of older people receiving domiciliary care. Inspection practices at the time of the report placed an emphasis on the records held by the domiciliary care service. The Commissioner recommended that the regulator seek feedback from the people using domiciliary care to ascertain effectiveness of the service in providing quality care. The report highlighted that RIQA's current small sampling of feedback on domiciliary care from people using domiciliary care was insufficient to provide a good overview of real experiences and relevant legislation does not place requirements on RQIA to have contact with the older person using the service.<sup>(160)</sup>

## **Implementation of standards**

In addition to regulating domiciliary care agencies, RQIA develop guidance documents pertaining to domiciliary care. The guidance documents help registered managers and social care workers make an informed decision regarding the delivery of a quality service for both staff and people using the service. They are aimed at complementing the standards, with an emphasis on training and regulatory requirements. RIQA have developed and published a number of guidance documents that are easily accessible on their website. These documents include guidance on medicine management, management of enteral feeding and adult safeguarding.<sup>(43)</sup>

### **3.5.11 Findings from Reviews**

There are a number of key documents that examine social care and or home support services in Northern Ireland. A summary of these documents will be outlined in the following section.

#### **3.5.11.1 Rapid learning review of domiciliary care in Northern Ireland (2020)**

*A Rapid learning review of domiciliary care in Northern Ireland (2020)* was conducted to examine domiciliary care during the COVID-19 pandemic and to inform future planning and practices.<sup>(181)</sup> The review focused on four themes: service user and carer experience, service provision, workforce experience and infection prevention and control. The findings concluded that there was a need for improvements in areas including: recognition of the domiciliary care workforce; support for domiciliary care workers, carers and family; meeting the needs of the person using the service; and policies, guidelines and training in infection prevention and control.<sup>(181)</sup>

#### **3.5.11.2 Department of Health reports 2011-2017**

The Department of Health in Northern Ireland has published many reports and recommendations on the health and social care system in Northern Ireland including:

- Transforming your care, a review of health and social care in Northern Ireland (2011)
- Who cares? The future of adult social care and support in Northern Ireland (consultation) (2012)
- The Right Time, the Right Place (Donaldson Report) (2015)

- Systems, not structures - Changing health and social care (Bengoa Report) (2016)
- Power to people, Proposals to reboot adult social care and support in Northern Ireland (2017).

All of these reports recognise that the ageing population of Northern Ireland has contributed to increased levels of frailty and chronic disease among older people. The model of health in Northern Ireland is reported as one that is 'reactive' and 'acute-centred' which subsequently may explain the aforementioned reports and the need for change. This is also reflected in annual surveys on domiciliary care, whereby statistical data does not show a significant rise or change in people using domiciliary care services in Northern Ireland, despite a call for change. For example, the number of people using domiciliary care services, be it from the statutory or independent sector was:

- 23,195 in 2017
- 23,409 in 2018
- 23,425 in 2019.<sup>(162)</sup>

Overall, the recommendations cover restructuring of HSC Trusts, leadership, accountability, shifting the focus of care including a person-centred approach, and listening to the experiences of people using services and workforce.

### **3.5.11.3 A Managed Change: An Agenda for Creating a Sustainable Basis for Domiciliary Care in Northern Ireland (HSCB 2015)**

A review conducted by the HSCB in 2015 entitled *A Managed Change: An Agenda for Creating a Sustainable Basis for Domiciliary Care in Northern Ireland* aimed to identify best practice in order to develop a preferred model for the delivery of domiciliary care in Northern Ireland.<sup>(163)</sup> This review acknowledged areas posing significant challenges associated with domiciliary care, such as operational and financial difficulties including variations in tariffs, procurements and statutory and independent markets across the HSC trusts and hence, could not identify a preferred model for the delivery of domiciliary care from any Trust.<sup>(163)</sup> The review concluded with a list of recommendations from their examination of domiciliary care that mainly aim to address the following:

- Restructuring of the Regional Social Care Procurement Group
- Establishment of a Community Care Forum or Task Force to oversee and monitor developments in domiciliary care

- Workforce planning and developing links with Domiciliary Working Group, NISCC - develop workforce strategies
- A managed approach to funding domiciliary support service and addressing demographic and cost pressures
- Research in outcome based models of domiciliary care as practiced in Great Britain
- Review and update the current Department of Health circular on domiciliary care to reflect current practices more accurately
- Developing an electronic monitoring system.

#### **3.5.11.4 Commissioners Summit on domiciliary care in Northern Ireland (2015)**

A report published by the Commissioner for Older People for Northern Ireland in 2015 examined the domiciliary care practices in Northern Ireland from a range of key stakeholders, including representatives from RQIA, HSCB, NISCC, National Institute for Health and Care Excellence (NICE) and the Department of Health. The Commissioner recommended that Northern Ireland take into account the NICE guideline NG21 *Home care: delivering personal care and practical support to older people living in their own homes* and embed them into the standards for the delivery of domiciliary care in Northern Ireland.

Issues associated with homecare practices in Northern Ireland are discussed in the Commissioner's Report, for example, time allowed for care workers to complete their care or tasks without being rushed. The Commissioner highlights findings of domiciliary care visits being reduced from 30 minutes to 15 minutes and in some cases visits had been reduced to eight minutes across Trusts. The NICE guideline (NG21) addresses this issue whereby the Commissioner advises that home visits of less than 30 minutes duration should not be used except in specific circumstances based explicitly on identified needs of the older person.<sup>(160)</sup> At the time of writing this review, the Department of Health in Northern Ireland has not nationally endorsed the NICE guideline, NG21 on homecare.

#### **3.5.11.5 10,000 Voices initiative**

The *Phase two regional report relating to care in your own home* was a survey and *10,000 Voices* initiative commissioned and funded by the HSCB and the Public Health Agency (PHA). This survey was conducted in 2014-2015 and asked carers, family members and people who receive care in their own homes to share their experience by 'telling their story'. A total of 1,399 responses were received from all Trusts. The survey included all community services, including domiciliary care, district nursing

and rehab and re-enablement. Overall, satisfaction with care provided at home was positive.<sup>(182)</sup> However, respondents also reported that their carers frequently had to rush and did not spend enough time delivering care needs. A small number (8%) reported that the impact of receiving care at home was negative or neutral (not sure). Reasons for this included:

- Inconsistency in the carers who provide the care
- Getting the care package established
- Needing additional help
- Timing and time allocation of calls
- Feeling safe in place of care.<sup>(182)</sup>

Of the 1,399 responses received from this survey, 60% were completed by a person receiving care and 23% were completed on behalf of person receiving care. A high percentage (79%) of respondents rated their experience of receiving their care at home as strongly positive or positive. A common theme highlighted was appreciation of being able to remain at home and remaining as independent as possible. Respondents also reported that their carers were kind, helpful, understanding, caring and compassionate and provided outstanding care.<sup>(182)</sup>

### **3.5.12 Summary and Lessons for Ireland**

In Northern Ireland, home support services are provided by statutory and independent care providers and is based on an assessment of need and eligibility criteria. The delivery of home support is governed and protected by a regulatory framework that is set out in national legislation. In addition, workforce within the sector falls under a regulatory framework. A lesson that can be drawn from Northern Ireland is the emphasis that is placed on the social care workforce and training. A strong theme across the literature is that of developing the domiciliary care workforce, recognising their contribution in health systems, improving working conditions, wages and providing education and training. This is also reflected in the legislation framework imposed on domiciliary care services, where sections 13, 15, 16, 17 of the Health and Personal Social Services, The Domiciliary Care Agencies Regulations (Northern Ireland) 2007 sets out arrangements that should be in place for social care workers and registered providers of domiciliary care services in Northern Ireland.<sup>(183)</sup> The nature of homecare results in it being largely unsupervised work and hence regulation of its workforce incorporating Standards and guidelines such as the *Northern Ireland Social Care Council Standards of Conduct and Practice for Social Care Workers, Standards for Employers of Social Workers & Social Care Workers 2017 NISCC Workforce Development and Qualification Guide* can serve to enhance the competency of care workers and quality of care delivery.

A report of the Commissioners Summit on domiciliary care in Northern Ireland in 2015 recommended that time allocated to social care workers undertaking homecare tasks should not be less than 30 minutes which is also recommended in NICE guidelines (NG21) on homecare.<sup>(160)</sup> Experiences reported from people using domiciliary care services in Northern Ireland have highlighted areas of dissatisfaction with care workers rushing and not spending enough time with them. A lesson that can be drawn from the Commissioner's report is reviewing time allocations for homecare that will support person-centred, quality and safe care to people using home support services. In addition, the Commissioner's report recommended that inspections carried out by RQIA place more emphasis on asking the older person using the service about their experiences of the care they receive.<sup>(160)</sup> Ireland can learn from this by placing a focus on the real life experiences of people using services such as home support. This outcome based approach may highlight areas of good practice and areas that require improvements.

Another lesson that can be drawn from Northern Ireland is learning from the challenges that have been reported. A review conducted by the HSCB in 2015 highlighted the challenges imposed by inconsistencies in what is meant by domiciliary care across the five Trusts in Northern Ireland.<sup>(163)</sup> This led to variations in operational practices and hence analysis of activity within the sector has been difficult to decipher. There is a need to develop a standardised definition and scope of what is meant by home support and what it constitutes, so that it can be adopted consistently across all Irish health and social care services. In addition, Northern Ireland use a standardised evidence-based tool *Northern Ireland Single Assessment Tool*. This tool places the older person at the centre of their own care needs and in doing so, promotes inter-professional collaborations. The adoption of a standardised tool such as the NISAT will offer a consistent and comprehensive approach to assessment and thus will reduce the likelihood of variations and risks in care delivery.

## **3.6 Wales**

### **3.6.1 Overview of home support services**

In Wales, formal home support services are referred to as domiciliary care. Domiciliary care is regulated by the Care Inspectorate Wales, under the Regulation and Inspection of Social Care (Wales) Act 2016. In 2019, the Welsh Government set out a strategic vision in their 10 year health and social care plan, that everyone in Wales should have longer, healthier and happier lives, able to remain active and independent, in their own homes, for as long as possible.<sup>(184)</sup> A 2021 Welsh Government White Paper states that more adults are receiving care and support at home wherever possible, but this has created a level of demand that outweighs the volume of domiciliary care provision available.<sup>(185)</sup> Accordingly, many people in Wales rely on family and friends for some or all of the care they need in the home. There are an estimated 370,230 unpaid carers in Wales, contributing care worth £8.1 billion per year.<sup>(186)</sup> This is the highest figure among all UK countries and is expected to rise to over half a million carers by 2037.<sup>(186)</sup>

This section will examine the landscape of formal home support services in Wales under the following headings:

- Model of home support service delivery
- Legislation
- Regulation
- Standards, guidance, policies and frameworks
- Findings from reviews
- Summary and lessons learned for Ireland.

### **3.6.2 The Model of home support service delivery**

This section begins by setting out an overview of the structure for home support services in Wales and how these services are delivered and governed. It then describes the scope of home support services in Wales and what tasks are included in care and support. The section then describes how a person's needs are assessed in Wales in order to determine their individual care and support requirements and funding for home support services. Finally, the domiciliary care workforce and how they are regulated is described.

### **3.6.3 Structure and governance**

The Welsh Government is the devolved government for Wales and it sets policy for health and wellbeing in Wales. The Department for Health and Social Services advises the Welsh government on policies and strategies for health and social care in

Wales. This includes contributing to relevant legislation and providing funding for the NHS and other related bodies. The Welsh Government legislates for domiciliary care.

Local authorities in Wales have a statutory responsibility for planning and commissioning social care in Wales. There are 29 main commissioners of care in Wales, through 22 local authorities and seven local Health Boards.<sup>(185)</sup>

The majority of domiciliary care funded by a local authority in Wales is delivered either by the independent or voluntary sector, who the local authority commission to meet the needs of eligible individuals. Some more specialist medical care is delivered by the community care teams from the local authority.<sup>(187)</sup>

In Wales, the NHS provides a package of care to those who have long-term and complex health needs, through a process called 'continuing healthcare' (CHC). CHC can take place in a variety of settings, including at home as domiciliary care. It is funded solely by the NHS to meet physical and mental health needs that are a result of disability, accident, or illness.<sup>(188)</sup> The NHS arranges and funds the appropriate care package for each recipient in order to best meet their needs.

The local health board (LHB) is responsible for planning outcomes, procuring services, and monitoring performance for all services for the individuals eligible for CHC. The LHB is also responsible for ongoing assessment in order to ensure that the correct services are being provided to satisfy patient needs.<sup>(188)</sup>

Domiciliary care is regulated by the Care Inspectorate Wales (CIW), an independent regulator who carries out inspections to ensure quality and safe care. In December 2019, there were 570 domiciliary support services registered with CIW.<sup>(189)</sup> Of the 570 domiciliary support services, 23 were provided by local authorities or local health boards.

Social Care Wales is the social care workforce regulator. It sets standards for, and develops the social care workforce and maintains the register of social care workers in Wales.

### **3.6.4 Scope**

Domiciliary care is formally defined by the Regulation and Inspection of Social Care (Wales) Act 2016 as follows:

The provision of care and support to a person who by reason of vulnerability or need (other than vulnerability or need arising only because the person is of a young age) is unable to provide it for him or herself and is provided at the

place in Wales where the person lives (including making arrangements for or providing services in connection with such provision).<sup>(190)</sup>

This regulated service includes the provision of supported living for people with additional care and support needs, and housing in purpose-built accommodation designed to facilitate the delivery of care to people. Providers of these types of services must ensure that the contractual arrangements they have in place with individuals using their services are separate from any contractual arrangements in relation to the accommodation provided.

Section 3 of the Regulation and Inspection of Social Care (Wales) Act 2016 defines care as the day-to-day physical tasks and needs of the person such as eating and washing, as well as the mental processes relating to those tasks and needs, such as remembering to eat and wash. Support is defined by the Act as counselling, advice or other help, provided as part of a plan prepared for the person receiving support by the service provider or local authority. A service providing support only does not meet the definition of a domiciliary support service.

The CIW sets out some of the activities likely to fall into the definitions of care and support for domiciliary services in their Regulation and Inspection of Social Care (Wales) Act 2016 - Registration Guidance.<sup>(191)</sup> These are shown in Table 3.7 below.

**Table 3.7: Care and support activities as described by CIW**

**Care includes:**

- Assistance with bodily functions, such as feeding, bathing and walking (including prompting the individual to do this)
- Assistance with managing continence (including prompting the individual to do this)
- Assistance with oral and dental care (including prompting the individual to do this)
- Administration of medication held in the premises where the individual lives (including prompting the individual)
- Assistance with getting dressed (including prompting the individual to do this)
- Assistance to maintain skin integrity (including prompting the individual to do this)
- Assistance with personal care involving intimate personal touching, such as shaving or nail care.

\*Note – these activities must be delivered where the person lives (within the physical premises that they are living in.)

**Support includes:**

- Assistance to attend appointments
- Assistance with trips out such as shopping or attending a place of worship
- Support to manage affairs, such as support to manage a tenancy agreement
- Supporting the individual to manage their money
- Assistance to maintain the security of a dwelling

**Source:** Regulation and Inspection of Social Care (Wales) Act 2016 - Registration Guidance.<sup>(191)</sup>

When considering whether a service is required to be registered, the Care Inspectorate Wales makes a holistic assessment of the activities being delivered. This assessment includes looking at the care and support plans and or risk assessments of those using the service.<sup>(191)</sup>

A 2020 review of alternative models of domiciliary support in Wales by the Wales Centre for Public Policy described domiciliary care as:

'the term used to describe social care provided in people's homes to help with daily tasks, managing medications, help to mobilise, personal care such as help with washing, and some clinical care such as catheter management and PEG feeding. It may also include re-ablement services which aim to maximise a person's independence, for example following a hospital stay'.<sup>(187)</sup>

### **3.6.5 Eligibility and assessment of need**

Depending on their needs, service users may be assessed by their local authority, the NHS, or both. This section details both eligibility assessment processes.

Under the Social Services and Well-being (Wales) Act 2014, local authorities have a legal duty to carry out an assessment of anyone living in its area who may need community care services, once it becomes aware of this need.<sup>(192)</sup> The assessment must take into account all aspects of person's needs. The Welsh Government have published a code of practice to assist providers in assessing the needs of individuals.<sup>(193)</sup> This Code of Practice sets out requirements for a National Assessment and Eligibility Tool as a way of ensuring a consistent approach to assessments and recording information. The National Assessment and Eligibility tool is a framework for recording and measuring progress against personal outcomes for those receiving care and support.<sup>(194)</sup>

The assessment and service provision process will generally consist of four main parts:

- An assessment of all the presenting needs and circumstances.
- A decision as to whether any of the assessed needs should be met by the local authority under the eligibility criteria (that is, a decision to provide services).
- If so, the nature and extent of services to be provided (the care and support plan).
- Financial assessment as appropriate (to determine how much you will need to contribute towards the cost of the services).

Social care support is generally means tested by the local authority to establish how much the service user must contribute towards the cost of care. When both health and social care services are needed, the NHS and local authority should work together in an integrated manner, with NHS services generally being free at the point of delivery.<sup>(192)</sup>

The National Framework for Implementation in Wales is the Welsh Assembly Government guidance document that sets out principles and processes to be followed when establishing eligibility for CHC through the NHS. It sets out to ensure fairness, consistency, and a good standard of care and outlines what is the responsibility of the LHB and what is the responsibility of the NHS. The Framework provides a national assessment process supported by a Decision Support Tool. The Framework and Tool were originally implemented in 2010 and was later reviewed and a revised document was published in 2014. In 2019, a second revision underwent public consultation.<sup>(188)</sup>

In order to qualify for continuing healthcare, the assessment is carried out by two or more nurses from the applicant's primary care trust. In conjunction with the National Framework, the Decision Support Tool is used. This tool is to be used to record rationale behind decision-making and to ensure consistency in assessment. This assessment is not means-tested and is based only on medical issues the applicant may have.<sup>(188)</sup>

Eligibility is decided based on whether the primary need of the applicant is a health need. Defining a primary health need is based on certain characteristics, alone or in combination. The assessment considers:

- Nature: the type of needs and the type of care required to manage them.
- Intensity: the extent and severity of the needs.

- Complexity: how different needs present and interact to increase the skill needed to manage care. This can arise with a single condition, or with multiple conditions and their interactions.
- Unpredictability: the degree to which needs fluctuate, increasing the challenge in managing them. It also relates to the level of risk to the person's health if adequate care is not provided.

These factors are also taken into account when deciding if a person is urgently in need of care. It is the responsibility of the local health board to carry out the assessment. If an individual has a rapidly deteriorating position, they may require 'fast tracking' for immediate provision of CHC, without going through the full eligibility process.<sup>(188)</sup>

### 3.6.6 Funding and Commissioning

People in Wales are expected to contribute to the cost of social care. The amount a person pays towards their care is determined by a means test. In Wales, regardless of a person's savings or income, there is a maximum weekly charge. To decide how much to charge, local authorities must carry out a financial assessment that is dependent on people's income and savings, the cost to an individual for social care is up to a maximum of £100 a week.\* The benefit rates are reviewed annually and the figures can sometimes change during the year.‡ The Welsh Government issued a code of practice Social Services and Well-being (Wales) Act 2014, providing detail to Local Authorities on charging and financial assessment, which includes guidance on charging for care and support in a care home.<sup>(193)</sup>

When an individual has been assessed as having a primary health need, domiciliary care to meet these needs is funded by the NHS through CHC, such that the cost of all care required to meet the assessed level of need is covered.<sup>(188)</sup> The NHS is not responsible for the cost of social work services, accommodation, food, general household support, or support for carers. The LHB is responsible for the provision of social services and there may be a charge to the recipient for some of these.<sup>(188)</sup>

A review of domiciliary care carried out by Care and Social Services Inspectorate Wales (now known as Care Inspectorate Wales) in 2016 found that approximately 14 million hours of care are commissioned each year in Wales, at an approximate cost of a quarter of a billion pounds.<sup>(195)</sup> They reported that this does not include care

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\* The person who use the service have to pay up to a maximum of £100 a week if they: 1) have a high level of disposable income; 2) have savings and investments over £24,000, not including the value of their home.

‡ Guidance from the Welsh Government website on charging for social care. Available from: <https://gov.wales/charging-social-care>

that is paid for privately, provided directly by councils, or care purchased using direct payments. They surveyed 283 people as part of this review and found of those receiving care, 17% were between 18 and 64 years old and 83% were 65 or older. 42% of people paid for some of their care, 30% said they paid for all care, and 28% said they did not pay for any care.<sup>(195)</sup>

The review found that arrangements for purchasing care were extremely varied which made the process unnecessarily difficult. The review found a “serious lack” of care and support capacity from formal care providers, which ultimately impacts on the individuals who receive care. The approach to arranging care in Wales at that time was described as “unsustainable” with lack of capacity in domiciliary care caused by workforce shortages and lack of flexibility or procurement and finance rules.

An outcomes-based homecare commissioning toolkit was developed by the Welsh National Commissioning Board, in partnership with the National Provider Forum in 2017.<sup>(196)</sup> Its purpose is to facilitate the development of an outcomes-focused approach to the commissioning of homecare services. The toolkit includes examples of best practice, references to other sources, research and resources that can help to inform practice of commissioners or homecare providers.

A 2020 Welsh review found that much of domiciliary care is still commissioned via a tendering process and on a ‘time and task’ basis, meaning that providers are paid an hourly rate for undertaking specific tasks.<sup>(187)</sup>

### **3.6.7 Workforce**

In 2014/15, approximately 20,300 workers were employed as domiciliary care workers, providing care to 39,500 people at a cost of £293 million over the two years. However most domiciliary care in Wales is provided by unpaid carers who provide approximately 96% of care.<sup>(197)</sup> Domiciliary care workers provide support for individuals in their own homes. They must register with Social Care Wales.<sup>(198)</sup>

There are three methods to register as a domiciliary care worker:

- register following induction
- register with a qualification
- register with experience.

New care workers can register by completing the All Wales Induction Framework (AWIF) for health and social care or the Social Care Wales Principles and Values Award during their induction period.

The AWIF is a workbook-based course which covers the principles, values, knowledge and skills workers need to carry out their role competently. The worker's manager can assess the workbooks and provide a certificate of completion.

The Social Care Wales Principle and Values Award course and assessment is a question and answer workbook and an online multiple choice assessment that managers nominate a worker to complete. Once registered, the care worker will need to complete a required practice qualification by the time they have to renew their registration in three years' time.<sup>(198)</sup>

Alternatively, care workers who have a Level 2 or 3 qualification in health and social care (Diploma, Qualifications and Credit Framework (QCF) or National Qualification Framework NVQ) or equivalent may apply to register on SCW online.

Finally, those without a required qualification but who have worked for three of the past five years in a relevant social care role may be assessed by their manager against required competencies.<sup>(198)</sup>

Domiciliary care workers are expected to follow the Code of Professional Practice for Social Care.<sup>(198)</sup> The Code sets out the standards for conduct and practice expected of those employed in the social care profession in Wales. It defines a social care worker as any paid worker contributing to the delivery of social care and support. The code is based on a person-centred approach with the following principles:

- Respect of the wishes and views of individuals
- Strive to establish trust between carers and individuals
- Promote the wellbeing, choice, and control of individuals and carers
- Respect the rights of individuals while ensuring their behaviour does not cause harm to themselves or others
- Act with integrity and uphold public trust and confidence in the social care profession
- Accountability for the quality of work and responsibility for development of knowledge and skills
- Those who are responsible for leading and managing staff must assist them in implementing the Code.

### **3.6.8 Relevant Legislation**

This section describes relevant legislation for the provision and regulation of domiciliary care in Wales.

In 2011, the Welsh government published the white paper Sustainable Social Services: A Framework for Action.<sup>(199)</sup> This set out a plan to create a new, integrated and person-centred approach to providing social services in Wales. To achieve this new approach, two pieces of primary legislation were developed.

- the Social Services and Well-being (Wales) Act 2014 and
- the Regulation and Inspection of Social Care (Wales) Act 2016.

A number of regulations followed on from the Regulation and Inspection of Social Care (Wales) Act 2016 and these will also be discussed. These are:

- The Regulated Services (Registration) (Wales) Regulations 2017
- The Regulated Services (Service Providers and Responsible Individuals) (Wales) Regulations 2017.

#### **3.6.8.1 The Social Services and Well-being (Wales) Act 2014**

The Social Services and Well-being (Wales) Act became law in 2014 and came into force on 6 April 2016.<sup>(200)</sup> The act covers adults, children and carers (adults or children who provide or intend to provide care and support).

The 2014 act changed the foundation of the social care sector and imposes duties on local authorities and health boards to focus on prevention and to work towards promoting the wellbeing of those who need care and support, or carers who need support. It changed the way people's needs are assessed and the way care is delivered, and aims to give people a greater voice and control as equal partners in decisions about their care and support.

The Social Services and Well-being (Wales) Act 2014 states that persons functioning under the Act must seek to promote the wellbeing of those receiving care, as well as carers. If an adult needs care and support, their needs must be assessed. The needs assessment must identify the outcomes the adult wishes to achieve in daily life and to assess what supports can assist them to achieve those outcomes. A local authority may require a person to pay a charge to the authority for providing or arranging the provision of care and support. Any charge imposed may cover only the cost that the local authority incurs in meeting the needs to which the charge applies. If a person is to be charged, the local authority must carry out a financial assessment to determine if it is practical for the person to pay the charge.

Social Care Wales describes the act as providing the legal framework for improving the wellbeing of people who need care and support, and carers who need support and for transforming social services in Wales.<sup>(201)</sup> The legal framework consists of three elements: the act itself; regulations which provide greater detail about the requirements of the act; and the codes of practice which give practical guidance about how it should be implemented.<sup>(201)</sup>

### **3.6.8.2 Regulation and Inspection of Social Care (Wales) Act 2016**

Part 1 of the Regulation and Inspection of Social Care (Wales) Act 2016 introduced a new system of regulation of care and support services in Wales, replacing that which had been established under the Care Standards Act 2000. The Regulation and Inspection of Social Care (Wales) Act 2016 provides the statutory framework for the registration and regulation of persons providing social care services which include domiciliary support services.<sup>(190)</sup>

This legislation establishes a system of regulation and inspection consistent with the ethos and principles of the Social Services and Wellbeing Act (2014) that is centred around people who need care and support, and the social care workforce. It moves away from a system based on the registration of establishments and agencies to a service-based model and places the quality of services and improvement at the heart of regulation.

The key objectives of this Act are to promote the wellbeing of service users and promote and maintain high standards in the provision of regulated services. There are five principles underpinning this Act:

- reflecting the changes brought about by the Social Services and Well-being (Wales) Act 2014
- putting people at the centre of their care and support
- developing a coherent and consistent Welsh approach
- tackling provider failure
- responding quickly and effectively to new models of service and any concerns over the quality of care and support.

Under the Act, domiciliary care services must be registered with Care Inspectorate Wales. In order to apply for registration, the regulated service must be specified, as well as the places from which the service will be provided, and a designated individual is named as responsible for each place. This Act also gives inspectors the power to enter and inspect any premises where regulated services are provided and

to interview persons related to the service, including service users and carers. An inspector may not enter and inspect private dwellings unless the occupier consents.

The Act also strengthened the provision for the regulation of social workers and social care workers. It renamed the Care Council for Wales and the Social services Improvement Agency as Social Care Wales and gave them more powers. The Act defines a social care worker as a person who is engaged in relevant social work, and who provides care and support to any person in Wales in connection with regulated services. The Act also sets out that a person is appropriately qualified as a social worker if they have completed a course that is approved by Social Care Wales (SCW) or satisfies any training requirements set out by SCW.

An easy-to-read version was developed by the Welsh Government for people receiving services and a summary of the Act specifically for young people.<sup>(190)</sup>

### **The Regulated Services (Registration) (Wales) Regulations 2017**

These regulations came into effect on 1 February 2018 and set out what information is required to be provided by an applicant or by a service provider for application of registration. In particular, it details the information required to be included in a statement of purpose for each place in relation to which service is to be provided.<sup>(202)</sup>

### **The Regulated Services (Service Providers and Responsible Individuals) (Wales) Regulations 2017**

These regulations came into effect on 2 April 2018 and cover care home services, domiciliary support services, secure accommodation services and residential family centre services.<sup>(203)</sup> A person who wants to provide a regulated service must make an application for registration specifying the regulated service that the person wants to provide. A person who is registered to provide a regulated service is referred to as a "service provider". The application for registration must specify the places at, from or in relation to which the service is to be provided. The application for registration must also designate an individual as the "responsible individual" in respect of each place at, from or in relation to which a regulated service is to be provided.

Parts 3 to 15 of the Regulations set out clear requirements on a service provider in relation to the standard of service that must be provided. These include requirements as to the standard of care and support to be provided. The Service provider must ensure that care and support is provided in a way which protects, promotes and maintains the safety and well-being of individuals and that care and support is provided to each individual in accordance with the individual's personal

plan. Service providers must ensure that care is provided with adequate skill and competence with regard to their statement of purpose. Part 11 is specific to domiciliary services and details requirements on service providers to:

- ensure a “schedule of visits” which delineates the time allowed for each visit and the time allowed for travel between each visit;
- offer domiciliary care workers on non-guaranteed hours contracts the choice of alternative contractual arrangements.

Parts 16 to 20 of the Regulations set out the duties placed on the designated responsible individual in relation to a regulated service. These duties include a requirement to supervise the management of the service, including the appointment of a suitable and fit manager. They are to ensure that there are effective arrangements in place for monitoring, reviewing, and improving the quality of care provided by the service. The intention is to ensure that a designated person at an appropriately senior level holds accountability for both service quality and compliance and ensures that there is a clear chain of accountability linking the corporate responsibility of the service provider and the responsible individual with the role of the manager of the regulated service.<sup>(203)</sup>

The regulations set out a detailed list of services that are not to be treated as domiciliary support services. Of note, these Regulations were amended in 2019 (Regulated Services (Service Providers and Responsible Individuals) (Wales) (Amendment) Regulations 2019) to exclude the provision of nursing care by a registered nurse from the scope of the definition of a domiciliary support service. These amendments also exempted care and support services provided by a Local Health Board related to a need for nursing care from domiciliary support services. The Welsh Government explained that these exclusions were introduced to provide clarity as well as avoiding unnecessary duplication and overlap between the two inspectorates. The intention is to avoid bringing services which relate to a nursing need and which may provide an element of care and support to individuals as an incidental part of that service into the scope of regulation by CIW. The Welsh government believed that this amendment would provide clarity for district nursing and community nursing teams which provide services intended to meet people’s nursing needs (and may provide care and support which is ancillary to the nursing need). NHS services fall within the oversight of Healthcare Inspectorate Wales.<sup>(189)</sup>

### **3.6.9 Regulation**

Assessment of domiciliary support services is carried out by the CIW using the Inspection Framework for care home services, secure accommodation services,

residential family centre services, and domiciliary support services.<sup>(191)</sup> The inspection framework is based on the principles set out within the Social Services & Well-being (Wales) Act 2014 and the Regulation and Inspection of Social Care (Wales) Act 2016 and specifically created using the Regulated Services (Service Providers and Responsible Individuals) (Wales) Regulations and the associated statutory guidance.

The primary focus of the inspection is consideration of the national wellbeing outcomes. The framework supports inspectors to consider how the service enables people receiving care to achieve their wellbeing outcomes and if the outcomes are poor, explore the reasons why through lines of enquiry in this framework. The framework defines wellbeing as:

- Securing rights and entitlements, and having control over one's own day-to-day life
- Physical and mental health and emotional wellbeing
- Protection from abuse and neglect
- Having access to education, training, and recreation
- Domestic, family, and personal relationships
- Contributions made to society and feeling valued
- Social and economic well-being
- Suitability of living accommodation.

In order to assess wellbeing, inspectors follow two main lines of enquiry: 'care and support' and 'leadership and management'. This inspection framework maps the 2017 Regulations and associated statutory guidance under these two lines of enquiry. When assessing care and support, inspectors take into account the suitability and quality of the service provided, and the personal care plan in place, as well as safeguarding of the service user. When assessing leadership and management, inspectors examine the overall governance and statement of purpose. They examine financial sustainability, the quality of staffing, the extent to which travel and care time are taken into account, as well as any procedures for dealing with complaints.

### **3.6.10 Standards, Guidelines, and Strategies**

Before the publication of the Inspection Framework, the National Minimum Standards for Domiciliary Care Agencies in Wales were used as the criteria to assess care. These Standards were introduced under the Care Standards Act 2000 which has since been replaced by the Regulation and Inspection of Social Care (Wales) Act 2016 and the associated 2017 Regulations. The National Minimum Standards

remained in force until 1st April 2018. This section begins with providing an overview of these national minimum standards, for information.

The section goes on to describe the statutory guidance issued for providers relating to the Regulation and Inspection of Social Care (Wales) Act 2016 and associated regulations. It then concludes with a summary of two Welsh national strategies that include reference to domiciliary care.

### **3.6.10.1 Standards**

#### **National Minimum Standards for Domiciliary Care Agencies 2004 (remained in force until 1 April 2018)**

Published by the Welsh Assembly Government in 2004, the National Minimum Standards for Domiciliary Care Agencies in Wales were the criteria used to ensure quality care and support was delivered to those receiving domiciliary care. They are no longer in force. These standards were described as minimum standards, which meant they set out a standard of service provision below which an agency providing personal care for people living in their own home must not fall. These standards were used to judge whether adequate personal care was being provided, and if the needs of the service users were being met. These standards applied to agencies providing personal care to a wide range of people who need care and support whilst living in their own home, including:

- older people
- people with physical disabilities
- people with sensory loss including dual sensory impairment
- people with mental health problems
- people with learning disabilities
- children and their families
- personal or family carers.

The Standards were grouped into five key topics and the outcome for service users was identified in relation to each theme. They are:

- User focused services (Standards 1-5) which covered keeping service users informed and ensuring the service is managed in a way that meets the individual needs of those receiving care.
- Personal care (Standards 6-10) which covered sustaining and supporting independence, and providing care in a way that treats the service user with respect and maintains their dignity.
- Protection (Standards 11-16) which covered health and safety of carers and service users. It also covers how to protect service users from abuse or exploitation.
- Managers and staff (Standards 17-21) which covered the quality of skill and competence expected of staff; both carers and managers.
- Organisation and running of the business (Standards 22-27) which covers maintaining a sound business infrastructure and ensuring that business premises are suitable and equipped for purpose.

The standards set out that in carrying out assessments, inspectors were required to have discussions with the service users, and their carers, families and friends. They were also to observe daily life in the home of the person who receives care and in the office of the agency providing said care. Finally, they assessed written policies, procedures, and records. Inspectors were expected to consider six themes when carrying out their assessment:

- A focus on the service users
- Fitness for purpose of the care providers
- Comprehensiveness of the care package provided
- Meeting assessed needs of the service user
- Provision of quality service
- Maintaining a competent and well trained workforce.

### **3.6.10.2 Guidance**

#### **Statutory guidance for service providers and responsible individuals of care home and domiciliary support services**

This statutory guidance was issued by the Welsh Ministers under the Regulation and Inspection of Social Care (Wales) Act 2016, and applies from April 2019.<sup>(204)</sup> It sets out how providers of regulated services can comply with requirements under the Regulation and Inspection of Social Care (Wales) Act 2016. Section 29(3) of the Act states that providers of regulated services and designated responsible individuals must have regard to this guidance in meeting requirements imposed by regulations under sections 27 and 28 of the Act.

The guidance sets out that the 2016 Act, the Regulated Services (Service Providers and Responsible Individuals) (Wales) Regulations 2017, and this statutory guidance replace requirements previously put in place under the Care Standards Act 2000 and the associated National Minimum Standards.

The statutory guidance provides further detail of the general requirements on service providers, and the CIW can take enforcement action against any registered service provider and responsible individual that does not adhere to these legal requirements. CIW use this guidance to inform decisions on whether to grant or refuse applications for registration as a service provider. This statutory guidance was used by the CIW to inform their inspection framework and sets out the requirements that inspectors use to assess services.<sup>(204)</sup>

### 3.6.10.3 Strategies

#### Care and support at home Five year strategic plan (2017)

Social Care Wales were asked by the Welsh Government to develop a five year strategic plan to improve care and support at home in Wales. The plan includes domiciliary care and support for adults and children, direct payments and the support provided by communities and unpaid carers. The five year strategic plan discusses how best to support people to live in their homes and receive good quality care and support. It focuses on providing flexible and consistent quality care to people, in line with the National Outcomes Framework. What matters most to people, according to the plan, is having a choice in their care, the relationships they form with their carers, being able to remain in their own homes, and receiving consistent services. This plan identifies several key areas for action.

1. Carers and those who receive care should be equal partners, who use their skills and decisions to make decisions together.
2. Care and support at home should be flexible, support personal outcomes, and meet the needs of the people receiving care. There must be clear information about how people can get care and support and independent advocacy should be available when necessary.
3. There should be investment in a range of good-quality options to help people stay independent and well. The Welsh Government should explore ways to increase resources to make care and support at home sustainable. There should be clear expectations of what people are expected to pay for and what the government is able to fund.
4. The workforce needs good knowledge, skills and values to provide care and support at home. There should also be strong leadership in place to ensure services provided are of good quality and make good use of available resources. Any workforce strategy must support the workers, allow for them to train and up-skill, and offer good pay and working conditions.
5. Care and support must be based on best evidence from academic and practice-based research.

An implementation plan has been developed for the five year plan<sup>(188)</sup> and is based on the following six outcomes:

- Outcome 1: Make sure people who need advice, care and support and carers, are equal partners who can use their skills, expertise and experiences to help make decisions
- Outcome 2: Care and support at home is built around the communities that matter to people

- Outcome 3: Care and support at home promotes individual outcomes and meets different needs
- Outcome 4: Investment in a range of good-quality options that help people maintain their independence and wellbeing
- Outcome 5: Make sure the workforce has the knowledge, skills and values to deliver outcome focused care and support at home
- Outcome 6: Care and support at home is influenced by evidence from academic and practice-based research.

For each of the six outcomes, the implementation plan includes objectives, impact, actions, lead partners and time frame.

### **A Healthier Wales: Our Plan for Health and social Care (2019)**

This 10 year plan published by the Welsh government sets out a long-term future vision of a “whole system approach to health and social care”, which is focused on health and wellbeing, and on preventing illness.<sup>(184)</sup> The plan emphasises a shift of services from hospitals to communities, and from communities to homes over the 10 years. The vision of the plan is that people will be supported to remain active and independent, in their own homes, for as long as possible.

#### **3.6.11 Findings from Reviews**

This section sets out findings from a number of reviews of Welsh health and social care services. These reviews either have a primary focus on domiciliary care or have included reference to domiciliary care within a review of the wider health and social care landscape. They are set out in chronological order ranging in date from 2016 to 2021. The section concludes with a summary of changes that have been introduced to domiciliary care in Wales as a result of the COVID-19 pandemic.

##### **3.6.11.1 Above and beyond - National Review of Domiciliary Care in Wales 2016 (CIW)**

This 2016 report sets out the findings of a national review of domiciliary care carried out by Care and Social Services Inspectorate Wales (now known as Care Inspectorate Wales) between August 2015 and March 2016.<sup>(195)</sup> The review set out to assess domiciliary care in Wales and to identify what worked well and what did not. The report made suggestions to improve practice and shape the regulations and guidance that were being developed at that time to support the new Regulation and Inspection of Social Care (Wales) Act 2016. It explored domiciliary care from the perspective of service users, care workers, care providers and care commissioners.

Providers explained that a large burden was placed on them by different councils having different arrangements for monitoring performance and that inspections were not intensive enough and did not focus on the things that mattered most. They expressed a desire for greater efficiency and more consistency in expectations by different inspectors. There was found to be a mismatch between expectations set out in the national minimum standards (in place at the time) and those of inspectors, with the suggestion that a more flexible, outcome-focused approach should be used. The report found that existing regulations and standards at that time to be 'narrow and ineffective' and that they did not focus enough on scheduling, internal quality assurance, and the well-being of staff.

The review found just how important personal relationships are between those who receive and give care.<sup>(195)</sup> Service users reported that social and emotional well-being was just as important to them as physical well-being and that trust and confidence in their care workers was crucial. Most respondents were happy with the care they receive most of the time and valued the relationships they had with their care workers. A small proportion experienced poor care, related to poor care worker continuity and unreliable visits. Despite poor pay and working conditions, most care workers were found to be very motivated and naturally concerned for the people they support.

When providers were asked if service users received continuity of care from staff they know, 100% responded either "always" or "mostly". Meanwhile, when assessed by the CIW, they rated only 71% of agencies as either excellent or good for continuity of care. It is possible that this discrepancy arises due to the use of different standards being applied. With regard to quality assurance, 27% of people said they were never or rarely asked for comments about their care and 10% were not confident that their complaints were addressed if they did raise them. Many care workers expressed that they felt under pressure and rushed to complete their tasks and travel between visits. Inspections found that care plans issued by social workers do not reflect outcomes and are not reviewed frequently, meaning they may be out of date and out of sync with people's needs.

### **3.6.11.2 The Parliamentary Review of Health and Social Care in Wales. A Revolution from Within: Transforming Health and Care in Wales (2018)**

This Parliamentary Review into Health and Social Care was established on a cross-party basis, to advise on the long-term future of health and social care in Wales and

published an interim report in 2017<sup>(205)</sup> and its final report in 2018<sup>(206)</sup>. The review concluded that new models of care must be co-designed and co-developed with the public and users of care alongside front-line health and social care professionals, and be underpinned by the design concepts set out in Prudent Healthcare, the Wellbeing of Future Generations (Wales) Act 2015, and the Social Services and Wellbeing (Wales) Act 2014.

The interim report highlighted that the number of people over the age of 65 in Wales is growing and the demand for care is increasing. The report stated that the number of over 65s needing local authority funded domiciliary care was predicted to rise by 47% between 2013 and 2030. The report highlighted that staff shortages were a significant problem facing domiciliary care in many areas of Wales and these shortages were largely due to uncompetitive pay and working conditions, with staff often having to perform tasks that they would not have to in less-skilled jobs that offer a more comfortable working environment. The report found that there is significant pressure on care services due to a large demand for care and pressures on funding and staff shortages.

### **3.6.11.3 Domiciliary consultation 2018**

The Welsh Government carried out a consultation seeking views on what changes should be made to improve the quality of domiciliary care services, as well as recruitment and retention of domiciliary care workers.<sup>(189)</sup> The document asked a series of questions around how the Welsh Government could increase the desirability of domiciliary care as a career and ways that would encourage workers to remain working in the domiciliary care sector.

When asked why they felt recruitment and retention of staff was difficult, 66% of responses felt that it was because of the low wages that domiciliary care workers were paid. Many of the responses also cited other issues (for example, work pressures (51%), unsociable hours (48%) and poor terms and conditions (47%)) that also confounded the matter.

Many respondents called for improved pay and terms and conditions, along with improved recognition of the sector as a skilled profession. Respondents cited improved access to training or opportunities to specialise in areas as ways of helping retain staff within the sector. Meanwhile, the topic of zero-hour contracts was controversial, with some responses arguing that zero-hours contracts only benefitted employers, who used them to save on their costs, while others felt that they provided greater flexibility to workers, and some could see that these contracts provided flexibility to both parties.

### **3.6.11.4 A practical legal guide for commissioners and procurement officers (2019)**

This 2019 review by Social Care Wales included an examination of current procurement of domiciliary support services in Wales and sets out recommendations for improving it.<sup>(207)</sup> The review explains that the current model for procurement is based on a 'time and task' specification. It describes this as an input-based model, where the provider is obliged to spend a particular amount of time with the client and carry out specific tasks such as wash, dress, feed and assist with medication. This review states that this model is inconsistent with the person centred 'needs based' requirements of the Social Services and Well-being (Wales) Act 2014, which changes the focus to outcomes. The report explains that a traditional 'time and task' specification within a care package does not allow for a flexible response towards the individual service user and can at times often reduce the need and drive for the user to maximise their own abilities and reduce the extent to which care is required. The review highlights that providers may not be skilled in delivering a different approach and they and their staff will need extensive support, training and assistance with moving to a person-centred approach.<sup>(207)</sup>

### **3.6.11.5 Alternative models of domiciliary care (2020)**

This review carried out by the Wales Centre for Public Policy in 2020 included a summary of challenges facing the existing model of domiciliary care used in Wales.<sup>(187)</sup> These challenges were identified as changing population demographics funding pressures and market fragility, current approaches to commissioning and workforce stability. The review highlighted that the COVID-19 pandemic has further highlighted the funding pressures in social care in Wales. The review explored alternative models of domiciliary care as possible responses to these challenges. It concluded there was no single or straightforward solution but outlined some practical examples and experience that could be used to develop higher quality, more person-centred care in the home.

The review found that much of domiciliary care is still commissioned via a tendering process and on a 'time and task' basis. Commissioning was highlighted as an essential element in developing alternative models of domiciliary care. The review recommended innovative commissioning that includes more personalised and outcomes-based approaches offering the potential to improve the quality of services for users.<sup>(187)</sup>

### **3.6.11.6 Rebalancing Care and Support (2021)**

The Welsh Government consultation white paper Rebalancing Care and Support sought views on the proposals to introduce new legislation to improve the social care system. The proposed changes included decreasing the complexity, increasing sustainability and strengthening integration. This white paper focused on three critical areas:

- refocusing the fundamentals of the care market – away from price towards quality and value
- reorientation of commissioning practices – towards managing the market and focusing on outcomes
- evolution of integration mechanisms – simplifying joint planning and delivery.

The Welsh Government proposed changes to the National framework for commissioning care and support for children and adults, including flexible fee methodologies, standardised commissioning processes and increased transparency of service performance. It proposed that the 'national office' for social care should be established to develop and deliver the proposed national framework by ensuring full engagement with stakeholders (for example, local authorities, health boards and independent sectors) and stability of the market for care and support, including workforce sustainability. The Regional Partnership Board (RPBs) role should remain to bring health and social care partners together along with representatives of citizens, carers and other critical voices to jointly review population needs and plan models of care and support. The changes proposed in this white paper aimed to rebalance the provision of social care and support to improve the quality of care for people who need care and support and carers who need support.<sup>(185)</sup>

The majority of the respondents to the consultation agreed that the complexity in the social care sector is inhibiting service improvement (71%), and the commissioning practices are excessively focussed on procurement (74%). Overall, the respondents agreed that the proposals to the new legislation are more simplified, focused on quality and social value, people's wellbeing and rooted in partnership and integrated working.<sup>(208)</sup>

### **3.6.12 Changes due to COVID-19**

On 30 April 2020, the Welsh Government published guidance on temporary modifications to some elements of the Social Services and Well-being (Wales) Act 2014, due to the powers created under the Coronavirus Act 2020. When absolutely

necessary, it is possible for local authorities to postpone usual duties. Under the Coronavirus Act 2020, local authorities:

- Do not have to carry out detailed assessment of care and support needs, though they must complete the assessments when modifications to the 2014 Act are no longer in effect.
- Do not have to carry out financial assessments, though they have the power to charge people retrospectively based on a financial assessment in line with arrangements under the 2014 Act.
- Do not have to prepare or review care plans, though they will “still be expected to carry out proportionate, person-centred care-planning which provides sufficient information to all concerned, particularly those providing care and support often at short notice” and must complete reviews once modifications to the 2014 Act are no longer in effect.
- Do not have to comply with requests to provide an individual’s preferred choice of accommodation.

### **3.6.13 Summary and lessons for Ireland**

In Wales, home support is referred to as domiciliary care and has been regulated since the introduction of the Care Act in 2000. In the past, regulations, standards and inspection methodologies brought in under the Care Act were criticised for a focus on process rather than outcome measures. Domiciliary care is now regulated by the Care Inspectorate Wales against a regulatory framework put in place under the Regulation and Inspection of Social Care (Wales) Act 2016. This has changed the way that services are registered and inspected, with more of a focus on well-being outcomes for people using services and improving quality of care and support. This transition provides valuable learning to Ireland in terms of its development of regulations and associated standards for home support services.

Domiciliary Care workers in Wales must register with Social Care Wales which has set out detailed requirements necessary for domiciliary care workers to register. Registration is flexible and the different options for training and registration make it easier for staff to do so. The Regulation and Inspection of Social Care (Wales) Act 2016 introduced steps to improve the quality of the care and support provided by the domiciliary care workforce, by requiring an increase in the separation between travel and call time and limiting the use of zero hours contracts. The domiciliary consultation carried out by the Welsh Government in 2018 shows that retaining staff is a difficult task, and that the staff themselves feel that good pay and terms and conditions contribute to retaining staff. Access to training and education was also

found to contribute to staff retention, as well as improving the skills of the existing workforce and ensuring that good quality care is provided to service users.

In the past, service providers in Wales expressed that they were put under pressure by different councils, with different arrangements for monitoring performance.<sup>(195)</sup> It is important that there not be any conflict in interpretation by inspectors as to what is laid out in standards and guidance. The 2016 'Above and Beyond' review revealed that in the past, service providers felt that inspections were inconsistent, go into insufficient depth, and do not focus on what matters most. Service providers expressed a desire for an outcome-focused set of standards, with greater flexibility and an emphasis on quality care and patient satisfaction. It is important that standards developed in Ireland for home support services are clear and consistent, outcomes-focused and are compatible with any regulations introduced.

It is clear from the Welsh reviews of domiciliary care that service users greatly value continuity of care and good communication with regard to their care. Dignity and independence are important to people. Most service users indicated that they were happy with the care provided to them, but felt that their carers were often stressed or in a hurry. In Wales, those receiving domiciliary care do so under an individualised care plan, though in the past it has been found that these care plans are not always reviewed frequently or kept up to date.<sup>(195)</sup> If Ireland is to set out requirements for care plans for individuals to be put in place, it may be necessary to set out how often these plans should be revised, in order to provide the best quality care. As per the Inspection Framework,<sup>(191)</sup> inspectors must consider quality and suitability of the care plan as part of their assessment.

## **3.7 The Netherlands**

### **3.7.1 Overview of home support services**

In the Netherlands, home support services, or *Thuiszorg* in Dutch, are a decentralised service, managed by municipalities. Health and social care services, including home support services, are funded by a mix of obligatory social and private health insurance, occasionally with additional co-payments for long-term care.<sup>(209)</sup> There are various packages of care available to service users, depending on their level of need and the tasks they need assistance with. Home support services in the Netherlands are regulated through a number of pieces of legislation, and Dutch law provides for a 'collective care obligation', which means that the state can be held responsible for ensuring that people can receive the care and support that they need.<sup>(209)</sup>

This section will examine the landscape of formal home support services in the Netherlands under the following headings:

- Model of home support service delivery
- Legislation
- Regulation
- Standards, guidance, policies and frameworks
- Findings from reviews
- Summary and lessons for Ireland.

### **3.7.2 The Model of home support service delivery**

In the Netherlands, home support services include all care delivered in the client's home, both medical care and assistance with daily living.<sup>(210)</sup> People receiving care and support have the option to choose their own homecare packages, paid for in a budget allocated by their municipality, funded through the mandatory national insurance scheme. Through this package of care, they can choose their own carers and what tasks they receive assistance with. Annually, approximately 600,000 people make use of Dutch homecare services.<sup>(211)</sup>

Care providers must satisfy several legal requirements.<sup>(212)</sup> For example, they must:

- deliver responsible care that meets the quality standards set by the relevant medical and professional associations
- make sure that only care professionals who are registered under the Health Professions Act (BIG) carry out certain regulated procedures
- discuss people's care plans with them
- provide for service-users' participation
- have a complaints procedure in place, and
- account for their quality management in annual reports.

These requirements are set out in the following acts:

- Healthcare Quality, Complaints and Disputes Act (WKKGZ)
- Healthcare Professions Act (Wet op de Beroepen in de Individuele Gezondheidszorg BIG)
- Care Providers (Patient Participation) Act
- Care Providers (Accreditation) Act.

Since 2003, clients are no longer assigned to a type of care provider, but a care indication is assigned by an independent organisation (CIZ) to a client, by which the client can choose a provider.<sup>(213)</sup> An indication states how much and what type of care a person needs. This has facilitated the entry of new competitors to the homecare market.<sup>(209)</sup>

### 3.7.2.1 Buurtzorg

The Dutch non-profit homecare provider Buurtzorg Nederland has attracted widespread interest for its innovative use of self-governing nurse teams. Rather than relying on different types of personnel to provide individual services, the approach taken by most home health providers, Buurtzorg is nurse-led and expects its nurses to deliver all relevant medical and support services to people in their own homes.<sup>(214)</sup>

The term 'Buurtzorg' means 'neighbourhood care' in Dutch.<sup>(214)</sup> The Buurtzorg model of care was first described in 2006 by Jos deBlok, with the aim of reducing costs and removing inefficiencies from the system. It places teams of nurses in a position of authority and responsibility for providing care to people in their own homes.<sup>(215)</sup> As of 2018, there are around 10,000 Buurtzorg nurses in 900 independent teams, caring for more than 70,000 patients a year.<sup>(216)</sup>

In 2018, long-term care costs amounted to 4.3% of the Netherlands' gross domestic product (GDP), more than in any other OECD country, but it is estimated that if Buurtzorg was to provide all homecare, the Dutch economy would save approximately €2 billion a year.<sup>(216)</sup> Furthermore, satisfaction of people receiving care and support through Buurtzorg is extremely high, according to results from government surveys.<sup>(214)</sup>

Buurtzorg consists of three components:

- self-governing teams of 10 to 12 nurses providing both medical and supportive homecare services
- an IT system relieving nurses of administrative tasks and allowing teams to self-monitor their performance, and
- regional coaches promoting best practice and offering advice as needed but without their own performance goals (introduced in 2007).<sup>(214)</sup>

There are several other key features of this model which are outlined in Table 3.8.

#### Table 3.8: Features of the Buurtzorg model

<p><b>Self-directed teams:</b> The Buurtzorg model trusts that the professionals hired to provide care do not need to be managed. Teams of up to 12 nurses self-manage their work and perform all tasks necessary to care for their patients. The teams themselves decide how to best perform their work, assign their own roles and schedules, and optimise team outcomes. As the teams operate on a small scale, they are able to know and use the local resources.</p>
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<p><b>Scope of practice:</b> Buurtzorg nurses work closely with GPs and other community care providers. Decisions are made in the home between the client and nurse, rather</p>
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than in an office. As the nurses provide comprehensive care, this enables a less fragmented delivery of care.

**Relationship-based Practice:** The relationship between nurse and client is a core part of this model. Teams work together to schedule care for their clients and ensure that clients receive care from only three or four nurses, to ensure a good continuity of care and to build relationships between client and care-giver.

**Simplified Billing:** The Buurtzorg model charges one rate for a visit, regardless of duration.

**Empowerment of clients:** The Buurtzorg model places an emphasis on improving clients' independence. Nurses work with their clients to teach them self-care and improve their confidence in achieving these tasks.

**Financial Sustainability:** As all care is delivered by nurses, they are able to reduce hours spent and on average use only 40% of the care hours allocated per client, resulting in significant savings.

**Low Overhead:** As the goal of the Buurtzorg system is to remove unnecessary management and administration, administrative costs have remained low.

**Employee Engagement and Satisfaction:** Buurtzorg nurses are encouraged to be creative and to have autonomy when working with their clients. This fosters a sense of satisfaction and wellbeing among nurses.

**Buurtzorg Web:** Teams are interconnected through an intranet called the Buurtzorg web that allows all nurses to share knowledge and extend and receive support. Business processes are organised through the web - all scheduling, billing, and documentation are carried out here. This allows teams to self-monitor productivity and budgets. It is estimated that the use of this platform for administrative functions saves approximately 20% of the costs of a typical homecare agency.

**Source:** Kreitzer (2015). Buurtzorg Nederland: A Global Model of Social Innovation, Change, and Whole-Systems Healing.<sup>(215)</sup>

The following section provides an overview of home support services in the Netherlands and is set out under these five sub-headings:

- Structure and governance
- Scope
- Eligibility and assessment of need
- Funding and commissioning

- Workforce.

### 3.7.3 Structure and governance

In the Netherlands, municipalities are responsible under the Social Support Act 2015 for ensuring that people receive the care and support that they need to live at home for as long as possible, including provision of domestic aid and some technical aids (for example, crutches or other mobility aids).<sup>(209, 217)</sup> The allocation and contracting of nursing and personal care services at home has largely been delegated to regional 'care purchasing offices' linked to the health insurance companies.<sup>(209)</sup> Through the care purchasing offices, municipalities decide on the eligibility of services and negotiate prices with providers.<sup>(209)</sup>

Access to support varies between municipalities. Some municipalities have a social support desk and others have set up neighbourhood social support teams.<sup>(218)</sup> The tasks of these teams also varies between municipalities, but in general they provide information about home support services available and arrange care and support for people.<sup>(217)</sup>

Providers of homecare in the Netherlands fall under umbrella organisations, such as ActiZ and BTN. ActiZ is an umbrella organisation that represents care agencies and institutions. It is a partner in discussions and deliberations with the government, patient organisations and health insurance companies. ActiZ is also an employer organisation that negotiates labour agreements. BTN is the other umbrella organisation, but represents exclusively homecare providers and is also involved in negotiating labour agreements.<sup>(209)</sup>

Monitoring of home support is shared by various organisations in the Netherlands. The Dutch Healthcare Authority (NZa) is a public body overseeing the proper functioning of the regulated market and is involved in cost control at a macro level, setting maximum prices, and safeguarding compliance with care insurance laws and advising the government.<sup>(209)</sup> The Dutch Healthcare Inspectorate (IGZ) is the regulatory and supervising authority for quality of care.<sup>(209)</sup>

The Health and Youth Care Inspectorate monitors the quality and safety of care under the Long-Term Care Act (WLZ) 2014.<sup>(219)</sup> They are an independent organisation that can impose administrative fines and penalties on care providers.<sup>(213)</sup> The accreditation of home support service providers is mandatory, and is carried out by the Dutch Institute for Accreditation.<sup>(14)</sup>

The Dutch Healthcare Authority ensures that healthcare services are provided efficiently and in accordance with the various acts, and controls healthcare costs.<sup>(24)</sup> Finally, the Netherlands Authority for Consumers and Markets supervises competition in the healthcare sector, in the interest of citizens who are reliant on the Long-Term Care Act (WLZ) 2014.

If a client receives both health and social care, the Inspectorate and the local municipalities share responsibility for supervising quality of care. The purpose of this collaboration is to identify risks and examples of good practice in care networks.<sup>(220)</sup>

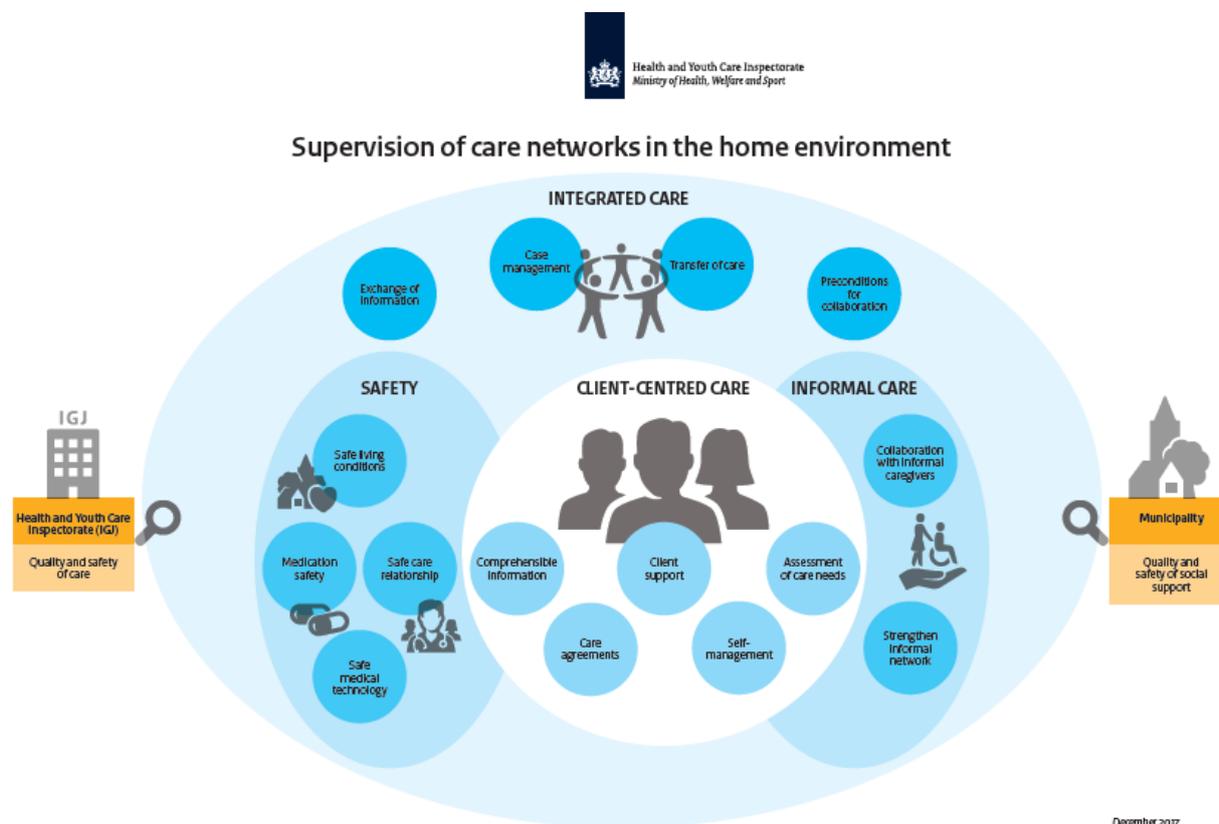
Responsibility for ensuring quality in home support services lies with the providers.<sup>(14)</sup> Two laws directly concern the quality of care. These are:

- Law on quality in care organisations (Kwaliteitswet zorginstellingen; KWZ) and
- Law on professions in personal healthcare (Wet op de Beroepen in de Individuele Gezondheidszorg; Wet BIG).

The Netherlands KICK (Quality Information Centre) supports healthcare organisations with current knowledge for daily practice.<sup>(221)</sup> KICK has 120 members from the following sectors: homecare, nursing homes, residential centres, mental health, disabled care, education and hospitals. Organisations that have a KICK membership have an active role in developing and exchanging practical up to date knowledge.<sup>(221)</sup>

In the Netherlands, healthcare providers deliver annual data requested in the set of performance indicators to the Health and Youth Care Inspectorate. These quality indicators cover issues such as staff (quality of work), financial performance, outcomes for the person, service delivery, and satisfaction of employees and quality outcomes. Any follow-up improvement activities is the responsibility of the organisation. Every two years a Quality Consumer Index is compiled, presenting users' experiences and preferences.<sup>(221)</sup>

**Figure 3.2: Supervision of care networks in the home**



**Source:** The Netherlands Government (2021). Supervision of Care Networks in the Home.<sup>(222)</sup>

### 3.7.4 Scope

This section outlines the scope of home support services provided in the Netherlands, and the various pathways through which these services are provided to people in different age groups and with different care and support needs.

#### 3.7.4.1 Zorg in natura (Care in Kind) (ZIN)

ZIN is care provided by an administrator that organises care and handles the administration. With ZIN, a person can choose to receive care in their own home through one or more providers. When it is provided by one provider, it is called the 'Full Home Package' and the package provided by multiple providers is called the 'Modular Home Package'.<sup>(223)</sup>

The Full Home Package consists of: <sup>(224)</sup>

- personal care
- nursing

- assistance with day-to-day activities
- day treatment
- transport to day care
- supervision and protection
- meals (food and drinks)
- maid service
- night care and 24-hour availability
- washing bedding and linens.

The Modular Home Package (MPT) can consist of several elements of the above 'Full Home Package' list, with the ability to combine nursing, personal care, home support, and daytime activities. MPT is suitable for those who do not require a full range of care. Meals are not arranged with an MPT.<sup>(225)</sup>

#### **3.7.4.2 Personal Budget (PGB)**

Unlike ZIN, the Personal Budget PGB is when a person, rather than an administrator, chooses and arranges their own care. Recipients are given funding based on their care need, assessed by the Care Assessment Centre.<sup>(226)</sup> PGB can be spent on:

- nursing
- grooming
- accompaniment
- transport
- keeping the living space clean
- lodging.

Recipients of the PGB decide on all aspects of their care, including by whom, where, when, and how the care is provided. They are responsible for recruiting their own care provider, drawing up a budget plan and signing a contract with the provider, which must include a description of the care to be provided.<sup>(227)</sup> The recipient is also responsible for keeping their own records and arranging replacement carers in the event of illness or holidays.<sup>(226)</sup> In order to pay for care, recipients make a declaration to the Sociale Verzekeringsbank (SVB) (Social Insurance Bank) who will then cover costs with the care provider.<sup>(227)</sup>

#### **3.7.4.3 Specialist care for older people**

In the Netherlands, GPs and district nurses are part of the core team in the care for older people living in their homes. Together with informal caregivers they ensure that the care meets people's care and support needs and enable them to live at home as long as possible.<sup>(228)</sup> The Health and Youth Care Inspectorate uses general

professional standards and professional guidelines, for example LESA 'Care for vulnerable elderly people' (2017), to inspect this.

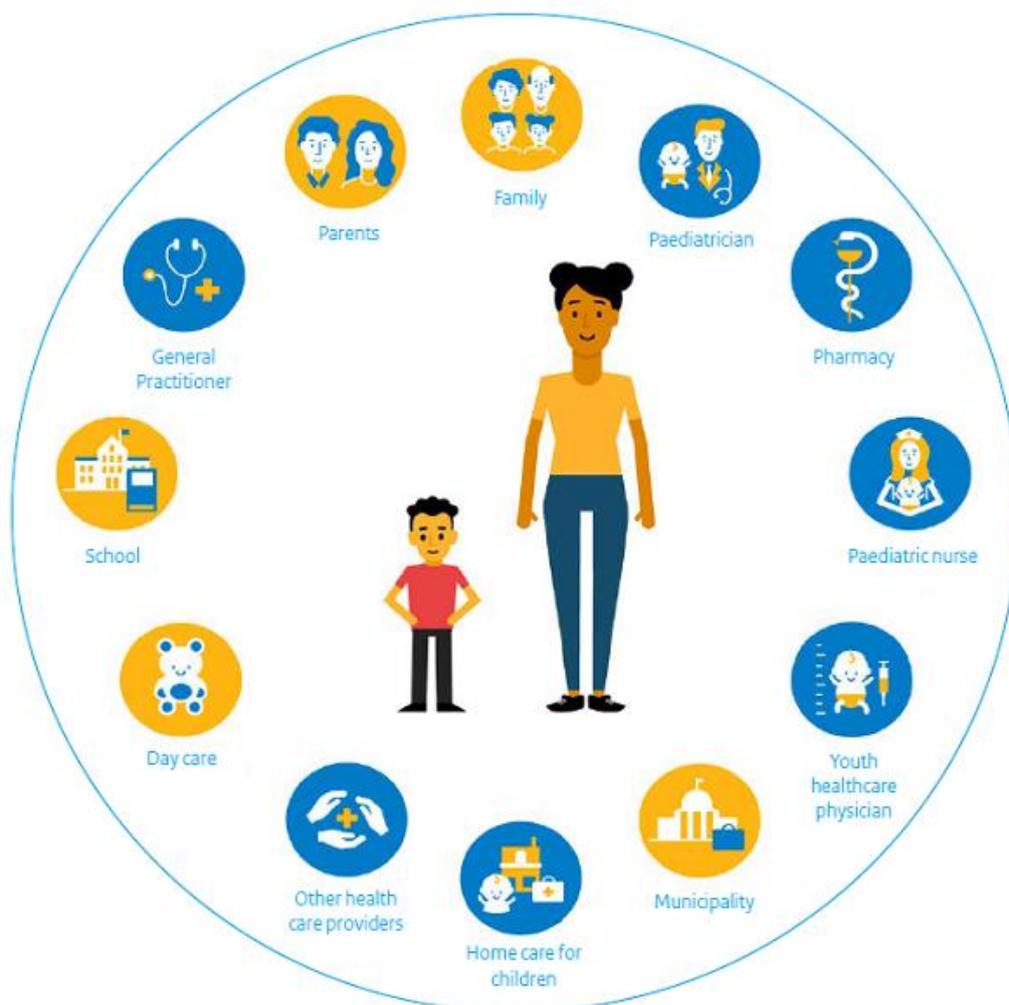
### Figure 3.3: Specialist care for older people



**Source:** The Netherlands Government (2021). Specialist Care Networks for Frail Older People (English version)<sup>(228)</sup>

#### 3.7.4.4 Specialist care for children

Specialist home nursing and care for children is provided in the child's home and their own environment wherever possible.<sup>(210)</sup> With this form of care, the paediatrician remains responsible for treatment of the child, but a variety of other health and social care professionals, such as homecare nurses, provide treatment and care. The GP is generally kept informed about the medical status of the child and their home situation, and there are often several care providers involved in the care network of the child.<sup>(227)</sup>

**Figure 3.4: Specialist care network for children**

**Source:** The Netherlands Government (2021). Specialist Care Networks for Children (English version)<sup>(229)</sup>

### 3.7.5 Eligibility and assessment of need

Eligibility for home support services in the Netherlands is not dependent on income, and all persons are entitled to apply for an assessment. However, co-payments for nursing and personal care services depends on income, household composition and age of the client.<sup>(209)</sup> On the other hand, home nursing that is financed by the compulsory health insurance is provided to all people who need it and is not subject to any other eligibility criteria.<sup>(209)</sup>

The Centre for Care Indication (CIZ) (Centrum indicatiestelling zorg) and its regional branches are responsible for carrying out eligibility assessments for nursing and personal care. Homecare nurses with a bachelor's degree have legal authority to

perform these needs assessments.<sup>(230)</sup> They apply nationally standardised criteria to look at a person's eligibility for home nursing and personal care, including possible alternatives and benefits already being received by the person who is being assessed.<sup>(209)</sup> If the client's situation changes, the type and intensity of care can be adapted by the provider within margins set by CIZ. Otherwise re-assessment can take place. Care professionals are responsible for monitoring the clients' needs for care.<sup>(209)</sup>

Seven criteria are used to aid the assessment of care needs:

1. general health status
2. limitations in functioning as a result of the disease or disability
3. the home and living environment
4. psychological and physical functioning
5. social circumstances
6. amount and duration of currently offered care
7. best suitable client profile.<sup>(231)</sup>

Eligibility for domestic aid support provided under the Social Support Act 2015 is assessed by the municipality.<sup>(217)</sup> Municipalities set their own criteria for access to domestic aid and supportive aids.<sup>(209)</sup>

### **3.7.6 Funding and Commissioning**

The share of GDP spent on in-kind social protection benefits (including homecare) is relatively high in the Netherlands compared to other EU countries.<sup>(209)</sup> Covering the cost of care is a responsibility shared between government, municipalities, and health insurers. Additionally, those receiving care may be asked to contribute towards the costs.<sup>(232)</sup> As of 2020, the maximum Social Support Act 2015 personal contribution a service user can be asked to pay is €19 per month.<sup>(233)</sup> All residents of the Netherlands are required to purchase healthcare insurance, covering the cost of their care.<sup>(214)</sup> The municipality may also award a personal budget which is paid into the Social Insurance Bank and the individual who arranges their own care pays for the cost through that budget. People with chronic illnesses and people with disabilities are eligible for welfare payments and tax reductions.<sup>(209)</sup>

The Buurtzorg model of care seems to have resulted in significant savings for the state in the care of the older people accessing this. It is reported that despite higher charges per hour, Buurtzorg has cut costs by reducing hours of care as well as hospital admissions by up to a third, and reducing the length of hospital stays.<sup>(216)</sup>

However, it has been suggested that these cost savings have resulted from the way in which people are chosen for Buurtzorg care and support.<sup>(214)</sup> In response to critics of the model, the Dutch Ministry of Health, Welfare, and Sport commissioned the consulting firm KPMG to conduct a study comparing Buurtzorg to other homecare providers, controlling for differences in patient characteristics. The results, published in January 2015, offer the best available evidence of Buurtzorg's performance on measures of cost.<sup>(234)</sup> They show that Buurtzorg is indeed a low-cost provider of homecare services, and that this effectiveness is not attributable to its patient mix. However, when patients' nursing home, physician, and hospital costs were added to the analysis, Buurtzorg's total per-patient costs were about average for the Netherlands.<sup>(234)</sup> The Buurtzorg model as a result would be disadvantaged if insurance companies were to base their contracts on per-hour rather than per-case costs.<sup>(234)</sup>

### 3.7.7 Workforce

There is a variety of levels of carers in the Netherlands. These 'levels' are representative of how many years the individual has undergone training for their role, and the higher the level, the more responsibility the carer has.<sup>(235)</sup> Not including nurses, there are three levels of carers:

- care assistants (level 1) undergo one year of vocational training
- homecare assistants (level 2) undergo two years of vocational training
- individual health carers (level 3) undergo three years of training, either full-time training or through an apprenticeship with an institution with a 24-hour work week and additional education days.

The content of training for carers and nurses is determined by the Ministry of Education, Welfare and Sports. The Ministry has formal minimum criteria for the education of all homecare professions for which qualification is needed. Educational institutes are subject to government inspection.<sup>(209)</sup> There are no specific training requirements for domestic aid assistants.

There is no mandatory registration for health and welfare assistants and care assistants but individual health carers (level 3) and nurses are required to register in the health professionals BIG-register.<sup>(235)</sup> Re-registration under the Individual Healthcare Professions Act (BIG Act) is required every five years. For re-registration, a minimum number of 2,080 working hours during the previous five years is required.<sup>(209)</sup> Additionally a voluntary quality registration for nurses does exist,

requiring nurses to have completed 184 hours of continued education during the previous five years.<sup>(209)</sup>

The Buurtzorg model of care has improved job satisfaction among the nurses working there, and has won Dutch Employer of the Year five times between 2010 and 2016. Over the years, it has scored between 8.7 and 9 out of 10 in general employee satisfaction. Other indicators of employee wellbeing have also been positive:

- lower staff turnover compared to other care providers (10% compared to 15%)
- consistently lower sickness absence - at about half the industry average
- higher homecare productivity (58% of hours billed to care as against 51% in other companies).

In the care for individual patients, homecare nurses are required to promote self-management by the patient and co-operate with informal carers.<sup>(209)</sup>

### **3.7.8 Relevant Legislation**

There is a variety of legislative acts in the Netherlands that cover homecare in the country. These acts lay the foundation for the health and social care system, with all residents required to purchase a basic health insurance package.<sup>(236)</sup> The Acts also set out how service users will be assessed and who is responsible for inspecting care providers. The next section provides an overview of the following acts in the Netherlands:

- Health Care Insurance Act 2006
- Long-Term Care Act 2015
- Social Support Act 2015.

#### **3.7.8.1 Health Care Insurance Act 2006**

In January 2006, the Health Care Insurance Act (ZVW) 2006 was adopted in the Netherlands, defining a basic health insurance package that covers all essential care.<sup>(236)</sup> Each person who lives or works in the Netherlands is obliged to take out health insurance, and there are regulations on what health insurers can charge for insurance. This ensures that nobody is excluded based on their health status or ability to pay.<sup>(236)</sup>

#### **3.7.8.2 Long-Term Care Act (2015)**

Implemented in 2015, the Long-Term Care Act 2015 applies to the most vulnerable groups in society in need of homecare, such as elderly people with advanced stage

dementia, those with serious physical or intellectual disabilities, or those with long-term psychiatric disorders.<sup>(232)</sup>

In order to receive care under this act, recipients must be assessed by the Care Assessment Agency, with healthcare administration offices being responsible for the implementation of care.<sup>(232)</sup> These offices are responsible for purchasing care and carrying out administrative tasks required, though those who manage their own needs through the PGB can choose their own providers. The Long-Term Care Act 2015 is a compulsory health insurance policy, paying a fixed percentage (9.65%) of income tax, on a maximum of €33,589 towards this policy.<sup>(232)</sup> In addition, those who make use of services under this act pay an income-dependent co-payment. This co-payment is also dependent on whether the client lives at home, is younger or older than 65, or is single, married, or has a domestic partner. All contributions go towards the Long-Term Care fund which is topped up by the government if funds become too low.<sup>(232)</sup>

Care provided under the Long-Term Care Act 2015 is described under a number of broadly defined categories:

- stay in a long-term facility
- personal care; assistance with washing, dressing, using the toilet, and eating and drinking
- care that increases self-reliance; assistance in structuring the day and learning to perform household duties
- nursing care and medical assistance
- medical, paramedical, or behavioural treatment which helps with recovery or improvement of a specific condition
- transport to day programmes and day treatment for those whose medical condition means they cannot travel independently.<sup>(232)</sup>

### **3.7.8.3 Social Support Act (WMO) 2015**

Under the Social Support Act 2015, local authorities are responsible for providing support to people with physical, mental, or psychological disabilities and the elderly, with the aim of increasing self-reliance and ensuring that people can continue to live in their homes.<sup>(217)</sup> Care is provided by local authorities who discuss with the client what support is appropriate. The Act sets out a basic quality standard for safe and effective care, but does not provide detailed rules about required quality. Care providers must adhere to any standards of its professional group and local authorities may set additional standards in the agreement with the provider.<sup>(217)</sup>

Tasks under the Social Support Act 2015 are financed by the central government via the Municipal fund. The central government decides how much is allocated to each local authority. Local authorities then decide how they spend their resources in implementing this act. Contracted support is paid by the local authority to the service provider, alternatively, people may arrange their own care with their personal budget (PGB).

### **3.7.9 Regulation and accreditation**

No obligatory accreditation applies to individual providers of any type of homecare.<sup>(213)</sup> However, compulsory registration does exist for agencies providing home nursing or personal care financed through the Exceptional Medical Expense Act (AWBZ).<sup>(209)</sup> This Act established an insurance scheme, as part of the country's mandatory health insurance system, which covers the high financial costs associated with serious, long-term illness or disorders.<sup>(214)</sup> The AWBZ imposes registration with one of the AWBZ care insurers as a condition for the entitlement to care.

Accreditation of home support services is carried out by the Dutch Institute for Accreditation.<sup>(14)</sup> It is based on meeting the following dimensions of care:

- client's perceptions
- outcomes for informal care
- service utilisation
- care workers' qualifications and satisfactions, and
- clinical outcomes.

Registration requires home support service agencies to comply with standards of accessibility of emergency care and transparency of administration and management.<sup>(209)</sup> In the Netherlands, healthcare providers deliver annual data requested in the set of performance indicators to the Health and Youth Care Inspectorate. These quality indicators cover issues such as staff (quality of work), financial performance, outcomes for the person, service delivery, and satisfaction of employees and quality outcomes. Any follow up improvement activities is the responsibility of the organisation. Every two years a Quality Consumer Index is presented, presenting users' experiences and preferences.<sup>(25)</sup> Quality improvement measures are generally the responsibility of home support service providers.<sup>(14)</sup>

#### **3.7.9.1 The Health and Youth Care Inspectorate**

The Health and Youth Care Inspectorate monitors the quality and safety of care under the Long-Term Care Act 2015. They are an independent organisation that can impose administrative fines and penalties on care providers who are not complying with legal requirements or professional standards and guidelines.<sup>(213)</sup> The Health and

Youth Care Inspectorate also inspect collaboration and integration of care between different care providers. The role of the Inspectorate is to "identify, set the agenda, and promote."<sup>(220)</sup>

The Health and Youth Care Inspectorate uses an assessment framework to assess quality of care by asking four main questions:<sup>(220)</sup>

1. Is the care person centred?
2. Do professional carers collaborate with informal carers?
3. Do professionals collaborate with each other to provide coordinated care?
4. Is the care safe?

In order to assess care, the Inspectorate talks with the client and their care providers. They look at the service from the perspective of the client and consider any informal care they may also be receiving. While the Inspectorate does not regulate or supervise informal care, it is considered an important component of the overall care that a service user receives.

In 2017, the Health and Youth Care Inspectorate developed a new inspection framework and working method for the supervision of care networks. The Inspectorate uses this inspection framework to assess networks of professionals who provide care to clients in home environments.<sup>(220)</sup>

The inspection framework contains the standards and criteria which the Inspectorate uses for supervising. These standards and criteria are based on laws and regulations, guidelines and field standards. Field standards, guidelines and legislation and regulations are continually being reviewed, therefore, the Inspectorate adjusts the inspection framework when necessary. This framework is only available in Dutch.

### **3.7.10 Standards, Guidance and Frameworks**

This section outlines the Standards, Guidance and Frameworks that are in place to support the quality of home support services in the Netherlands.

#### **3.7.10.1 Standards**

While efforts to set standards were previously carried out under the Quality Framework for Responsible Care, there are no home support standards in the Netherlands.<sup>(237)</sup> Some municipalities use tools such as the Dutch self-sufficiency matrix or participation ladders, which measure the extent to which each person can participate in society, while other municipalities do not use a tool to monitor standards of care.<sup>(238)</sup> The Social Support Act 2015 sets out the principles of independence, participation, and customisation of support as principles that service providers should strive for.<sup>(217)</sup>

Instead of National Standards, Dutch providers of home support services use the Consumer Quality Index and its quality domains to develop tools for self-assessment and surveys of people's experiences of using their services.

### **The Consumer Quality Index (CQ Index)**

In 2006 the Dutch Ministry of Health, Welfare and Sport mandated the development of a national standard for the measurement and comparison of consumer experiences in healthcare, called the Consumer Quality index or CQ-index®.<sup>(14)</sup> CQI is a registered trademark that is owned by the Centre for Consumer Experience in Health Care (Centrum Klantervaring Zorg). This Centre is a private foundation with a tripartite board (with members from patient and or consumer organisations, health insurers, and healthcare providers), funded by the Ministry of Health, Welfare and Sports. The CQI trademark is used to certify that information about the performance of health care providers is valid, reliable, and comparable.<sup>(239)</sup> In the CQI, questions about people's experiences, rather than their satisfaction, are combined with questions about values and expectations with regard to healthcare.<sup>(239)</sup>

The CQ-index is a standardised system for measuring, analysing and reporting service users' experiences. The information from the CQ-index can be used by:

- people seeking care and support, to help them to choose an insurer or provider
- advocacy organisations who represent the interests of their members
- insurers
- managers and professionals who want to improve their quality of care, and
- the Health and Youth Care Inspectorate to improve its functioning.

The CQ-index shows the quality of care from the person's perspective in a standardised way and provides insight into what clients find important.<sup>(221)</sup>

All providers of long-term care, including home support services, are required to carry out surveys of users' experience using the CQ-Index for homecare every two years.<sup>(209)</sup> This national tool, used to measure and compare experience, was developed based on 10 quality domains outlined in the Quality Framework for Responsible Care. These domains are:

- Care or life plan
- Communication and information
- Physical wellbeing
- Safety of care
- Domestic and living conditions

- Participation and autonomy
- Mental wellbeing
- Safety of living environment
- Sufficient and competent personnel
- Coherence in care.

Each domain has an associated set of indicators developed on the basis of the structure-process-outcome concept. The indicators provide a picture of what users find important and what their experience with care is.<sup>(14)</sup>

Municipalities are obliged to annually assess their clients' satisfaction with domestic aid services and there is a special CQ index for this purpose.<sup>(209)</sup>

### **3.7.10.2 Frameworks**

This section outlines the frameworks for home support services in the Netherlands.

#### **Quality Framework for Responsible Care 2007**

In the Netherlands, the Quality Framework for Responsible Care (QFRC) was launched in 2007. The QFRC contains measurable indicators that show whether the organisation provides responsible care. Health and social care professionals are actively involved in the preparation and execution of measurements. The QFRC is an important part of the professionals' work and connects with the ambitions of professionals to deliver responsible and 'good' care. Results showing whether or not care providers are meeting the indicators in the QFRC provide a basis for further discussion with professionals. In this discussion, the results can directly be translated into tangible improvements and adjustments in programmes and practices.<sup>(221)</sup> The results of the QFRC are displayed, on a voluntary basis, on the website KiesBeter ('choose better'). The intention of presenting these results is transparency of data and to encourage organisations to improve their quality of care.

#### **Inspection framework and working method for supervision of care networks**

In 2018, the Health and Youth Care Inspectorate developed an inspection framework and working method for the supervision of care networks. The Inspectorate uses this inspection framework to assess networks of professionals who provide care to clients in home environments.<sup>(227)</sup> The inspection framework contains the standards and criteria which the Inspectorate uses for supervising. The Inspectorate continually updates the inspection framework as the need arises.<sup>(227)</sup> The framework is only available in Dutch.

### **3.7.11 Findings from Reviews**

This section provides a summary of reviews which have looked at homecare in the Netherlands. These are the:

- The Social Support Act 2015 in practice (2018)
- Approaches to the regulation and financing of homecare services in four European countries, Health Research Board (Ireland) (2017)
- Health and Youth Care Inspectorate Review of Specialist Care for Children (2018).

#### **3.7.11.1 The Social Support Act 2015 in practice (2018)**

This review found that the principles of the 2015 Act are well received by providers and service users but suffer from difficulties with implementation.<sup>(218)</sup> There is some uncertainty on how to translate the principles of independence, participation, and customisation of support into real-world practice. In particular, the definition of 'independence' is complex for certain groups, such as people with dementia.

The 2015 Act was also found to vary in its application in different municipalities, with different areas reflecting different visions and priorities. Several stakeholders expressed dissatisfaction about the process of accessing support, while providers were critical of how the administrative burden, caused by rules, procedures and accountability systems, varied between municipalities.

In general, the 2015 Act was found to encourage collaboration within municipalities and between the municipality and third parties. Municipalities were more likely to seek contact with providers, link the 2015 Act to other policies, and join up with other municipalities in partnerships. However, friction was sometimes felt between the 2015 Act and other less flexible acts such as the Long-term Care Act (2015) and the Health Insurance Act (2006.)

As of 2016, municipalities were reported to be focusing on organising the 2015 Act in their local setting, with some difficulty in defining outcomes such as independence or participation. They were reported to still be searching for suitable ways to measure and monitor these outcomes.

### **3.7.11.2 Approaches to the regulation and financing of homecare services in four European countries, Health Research Board (Ireland) (2017)**

In 2017, the Health Research Board in Ireland carried out a review of regulation and financing of homecare services in four European countries, including the Netherlands.<sup>(116)</sup>

The HRB review noted that in the Netherlands, choosing their own care provider gives service users more choice, however the budget they are allocated is often smaller than if they were assigned a care provider. People are also typically assigned a smaller budget if they live with family, as there is an expectation that the family member will provide informal care. The HRB review found that over the years, the number of people opting for the personal budget system meant that it has been somewhat curtailed since 2012. In some cases, municipalities can decide not to issue a personal budget for domestic help services.

Positively, the review found that homecare in the Netherlands was relatively low-cost care and had short waiting times. All citizens are entitled to affordable, quality care which ensures equity. However, as municipalities are able to direct unspent funds into areas other than homecare, they are incentivised to maintain a low cost of care and this pressure may result in the provision of fewer hours of care, or an increase in the payment required from the service user in the future. At the time of the HRB review, the provision of homecare in the Netherlands did not fall short of needs, and the review reported that decentralisation of homecare and various Acts should serve to make homecare sustainable in the long-term.<sup>(81)</sup>

### **3.7.11.3 Health and Youth Care Inspectorate Review of Specialist Care for Children (2018)**

The Health and Youth Care Inspectorate examined the overall care and treatment in care networks and had several recommendations to improve how this is delivered. It was suggested that there needs to be more clarity about the way in which the paediatrician fulfils their role as the professional with ultimate responsibility for the care and support of the child, as GPs do not appear to play a big part in children's care networks at home.<sup>(229)</sup> Further recommendations following this review were as follows:

- parents or primary caregivers should be supported as they have a major role in managing the child's care and support
- coordination between paediatricians and other health and social care professionals should be highlighted and improved

- there should be more unity in terms of policy, and regular consultation, coordination and evaluation are needed
- there should be more detailed guidelines for nurses and greater clarity about how to carry out care needs assessments
- service providers must comply with legislation and regulations
- more attention needs to be paid to medication safety.<sup>(210)</sup>

### **3.7.12 Summary and lessons for Ireland**

As a country that has made large changes to their home support system in recent years, there are several lessons for Ireland to be taken from the Netherlands.

The Netherlands offers a variety of homecare packages that allow for tailoring to individual people's needs. It is clearly set out what is offered within each package and who it is appropriate for. The 'Full Home Package' is a comprehensive care package, while the 'Modular Home Package' is more suited to those who have a greater degree of independence. Finally, should one wish to, it is possible to entirely arrange one's own care, allowing for the greatest degree of customisation.

The Buurtzorg model proposes, by being nurse-led, to reduce administrative costs. Additionally, nurses working under this model report greater work satisfaction, as they have greater control over their work. This model also allows for good continuity of care. However, it is interesting to note that the net benefits of Buurtzorg have been disputed by critics of the model, in particular, the potential for the model to lead to cost savings for the state.

There are no national standards for home support services, or for health and social care, in place in the Netherlands. Instead, the Health and Youth Care inspectorate develop tools based on their Consumer Quality Index for measuring the experience of people using health and social care services, for example, the CQ Index for Long-Term Care. Having a focus on the person's experience allows for an outcomes-focused approach to quality improvement, however it is unclear how professionals translate this into daily practice in a standardised way. The quality indicators contained within this CQ Index may offer an insight into this, however these were not available online in English.

In the Netherlands, care is decentralised and each municipality is responsible for setting their own standards and managing their own funding. While this allows for municipalities to tailor care to the needs of their local community, it does mean that the quality of care potentially varies between municipalities. Providers have criticised how administrative burden can vary between municipalities. There is no one clear method to examine the standard of care against the principles of participation, independence and customisation of support set out in legislation in the Netherlands.

Thus, any standards created for home support in Ireland, must include a clear description of what high level principles mean for the person using the service and what they would look like in practice for the service provider, to help ensure a consistent quality of care, regardless of provider.

## **3.8 New Zealand**

### **3.8.1 Overview of home support services**

New Zealand has a publicly-funded, universal health and disability system<sup>(240)</sup> which has a strong focus on people remaining independent and living in their communities for as long as possible. Home support services operate under Home and Community Support Services (HCSS) in New Zealand. HCSS are delivered by a complex system of organisations, with each contributing to the needs of the services and New Zealanders. They are underpinned by legislative and policy frameworks led by the Ministry of Health. As such, commitment to the integration and coordination of services is integral to the provision of safe and quality HCSS services. This is evident in New Zealand where there is a comprehensive approach to monitoring and certifying service providers against evidence-based standards, which focus on outcomes and experiences for the person using the services. New Zealand has a diverse ethnic population<sup>(240)</sup> and strives to achieve an equitable health system for all New Zealanders, which is set out in legislation and is a prominent feature in government health policies, strategies and auditing processes.

This section of the review provides a summary of how home support is delivered in New Zealand. It sets out the governance structures, key organisations involved in home support and key pieces of New Zealand's legislation that relate to home support services. This section is set out under the following headings:

- Model of home support service delivery
- Relevant legislation and regulation
- Standards, guidance, policies, frameworks and implementation
- Findings from reviews
- Summary and lessons for Ireland.

### **3.8.2 The model of home support service delivery**

This section describes the landscape of home support across New Zealand and is set out under the following sub-headings:

- Structure and governance
- Scope
- Eligibility and assessment of need
- Funding and commissioning
- Workforce.

### **3.8.3 Structure and governance**

Home support services are provided through health and disability services in New Zealand. The Ministry of Health develops policy for health and disability care and has overall responsibility for the management and development of the health and disability system in New Zealand. The Ministry of Health is made up of a number of business units, each with its own functions and areas of responsibility. This section will give a brief description of the key organisations that are significant to home support in New Zealand and operate across these business units. The key organisations are:

- District Health Boards
- HealthCERT
- Accident Compensation Corporation
- Standards New Zealand
- The Home and Community Health Association.

#### **3.8.3.1 District Health Boards**

There are 20 district health boards (DHBs) that are responsible for planning, managing, providing and funding health services for the population of their district. These services include primary care, hospital services, public health services, aged care services, and services provided by other non-government health providers. Each DHB is governed by a board of elected members that set the overall strategic direction for the DHB and are accountable to the Minister of Health. The National Health Board, a business unit of the Ministry of Health, funds and allocates resources and monitors the DHBs. A DHB aims to:

- improve, promote and protect the health of people and communities
- promote the integration of health services, especially primary and secondary care services
- seek the optimum arrangement for the most effective and efficient delivery of health services in order to meet local, regional, and national needs
- promote effective care or support of those in need of personal health services or disability support.

#### **3.8.3.2 HealthCERT**

HealthCERT is a department in the Ministry of Health with a responsibility to administer and enforce the legislation, issue certificates, review audit reports and manage legal issues. It promotes the safe provision of health and disability services to the public. It also has a regulatory role for ensuring hospitals, rest homes,

residential disability care facilities and fertility services provide safe and reasonable levels of service for people who use services, as required under the Health and Disability Service (Safety) Act 2001. However, its regulatory function is for overnight services only and hence does not include HCSS.

### **3.8.3.3 Accident Compensation Corporation**

The Accident Compensation Corporation (ACC) is a state organisation or Crown entity responsible for administering New Zealand's no-fault accidental injury compensation scheme. The scheme provides financial compensation and support to citizens, residents, and temporary visitors who have suffered personal injuries. This includes children, beneficiaries, students and tourists. Employment status does not impact a person's cover. Everyone in New Zealand is covered by this ACC no-fault scheme for costs of treatments from an injury that is deemed as an accident, including payment towards treatment, help at home and work, and help with your income. Payments from the ACC scheme is dependent on an assessment of the injury and level of impairment as a result of the injury. Registered health and service providers governed by the Accident Compensation Act 2001 as a treatment provider or registered health professional can register with the ACC. The ACC is funded through a combination of levies and government contributions.

### **3.8.3.4 Standards New Zealand**

Standards New Zealand is a business unit of the Ministry of Business, Innovation and Employment that is within the New Zealand Government. This unit specialises in managing the development of standards and standards-related products, as well as publishing and selling New Zealand, joint Australian and New Zealand and international standards. This includes standards relative to all industries including the health and disability sector in New Zealand. Standards New Zealand is not a certification body, so it cannot determine whether services comply with standards. This role is fulfilled by organisations or business units separate to Standards New Zealand.

### **3.8.3.5 The Home and Community Health Association**

The Home and Community Health Association (HCHA) is a non-governmental organisation that represents the providers of home and community health services in New Zealand. Its overall objectives are to provide leadership and advocacy to the sector and to establish, promote and recognise high standards of practice. The association maintains relationships with government in developing the needs of the sector, including their members' education and information needs. HCHA is governed by a Board. Six members are elected by the membership for their skills and ability to

strengthen the home and community health sector. HCHA provides a list of providers on their website. The HCHA have 55 member organisations providing personal care, palliative care, household support, carer support and nursing care. In addition, a report from the HCHA submitted to the Minister for Health in 2020 highlighted that more than 101,000 elderly and vulnerable people living in New Zealand are living independently in their own home due to the care and support received from providers associated with the HCHA organisation.<sup>(241)</sup>

### 3.8.4 Scope

Home support services fall under the umbrella term of Home and Community Support Services (HCSS) in New Zealand. The Ministry of Health categorises home support under Household Management and Personal Care.

Household Management includes help with the following:

- preparing meals
- washing, drying or folding clothes
- house cleaning, vacuuming and tidying up.

Personal care includes help with:

- eating and drinking
- getting dressed and undressed
- getting up in the morning and getting ready for bed
- showering and going to the toilet
- getting around your home.

In New Zealand, over 100,000 people receive support from the HCSS sector. The characteristics of these people are predominantly in older age groups. A report published on behalf of the HCHA in 2019 identified 71% of people using HCSS as being over the age of 65 years, with 41% over the age of 85 years. It also identified that 58% of people were living with at least one chronic condition and 56% were at risk of hospital or residential care admission.<sup>(242)</sup> A report from the Director-General's Reference Group for In-Between Travel in 2015 reviewed the delivery and funding of HCSS and issues facing the sector. This report was in response to the In-Between Travel Settlement Agreement where it was agreed to pay employees for time spent travelling between client homes including travel mileage. This report grouped people using HCSS in New Zealand according to their different needs and funding arrangements as follows:

- people with health needs, including older people (aged 65 and over), people with long-term medical conditions, and those requiring short-term care following discharge from hospital (funded through DHBs)
- people with disabilities (funded directly through the Ministry of Health)
- people recovering from injury, or living with the long-term effects of injury (funded by ACC).<sup>(243)</sup>

Home Support services in New Zealand are services that can help a person to maintain independence, quality of life and stay at home for as long as one can participate in their community.<sup>(244)</sup> There are approximately 75 service providers of HCSS throughout New Zealand that are contracted to DHBs, ACC and disability support services. The variety of providers includes large, medium-sized and small private providers, iwi§ based providers and charitable providers and providers can have contracts with several DHBs.<sup>(245)</sup>

Home support services provide:

- personal care (for example, getting out of bed, showering, dressing, medication management)
- household support (for example, cleaning or meal preparation)
- carer support (help for the person who lives with and or looks after a person for four hours or more each day)
- equipment to help with safety at home.

### 3.8.5 Eligibility and Assessment of need

In order to receive publicly-funded home support services in New Zealand, a person must meet the eligibility criteria for home support. The first criteria is being a New Zealand citizen or resident who is eligible for publicly-funded health or disability services under the New Zealand Public Health and Disability Act 2000. This eligibility gives a person the right to be considered for publicly funded health or disability services, be it free or subsidised. The Ministry of Health provide the following definitions for an eligible person:

A person with a disability is someone who has been identified as having a physical, intellectual, or sensory disability (or a combination of these) which is likely to continue for a minimum of six months and result in a reduction of independent function to the extent that ongoing support is required.<sup>(246)</sup>

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§ Iwi means people or nation.

An eligible older person is someone who has been identified as having an age-related disability which is likely to continue for a minimum of six months and result in a reduction of independent function to the extent that ongoing support is required.<sup>(246)</sup>

An eligible person is a person who has a mental health diagnosis and requires a key worker to access community supports, however the keyworker is not required for the duration of supports and the person can be referred to primary care and remain eligible. A person with an alcohol and or drug addiction diagnosis must have a co-existing mental health diagnosis to be eligible.<sup>(241)</sup>

In addition, a person must also meet clinical and assessment criteria to receive home support services. DHB provides a Needs Assessment Service to assess eligibility and this is determined by a Needs Assessment Service Co-ordination (NASC) organisation. These organisations facilitate needs assessment, identify support needs, plan and coordinate services and allocate resources within a pre-determined budget.<sup>(240)</sup> They are contracted by the Ministry of Health or District Health Boards to serve:

- children and adults with disabilities
- people with mental health issues
- older people needing age-related support.

The NASC may specialise in one or all of these areas. There are 15 younger peoples' NASCs and 21 older peoples' NASCs throughout New Zealand.<sup>(247)</sup> Figure 3.5 displays the pathway to needs assessment and receiving support services.

**Figure 3.5: Pathway to needs assessment and receiving support services**

**Source:** NASC, New Zealand Ministry of Health (2011). Needs Assessment and Support Services for Older People: What you need to know.<sup>(244)</sup>

The DHBs must prioritise access to services and hence people with the highest needs will receive home support services first. The involvement of informal care, for example family members or whānau\*\* are also taken into account when assessing the needs of the person. Referrals to a Needs Assessment Service are by self-referral or by a doctor, community health worker, family member or a friend, providing the person who needs the assessment has given consent. The person who carries out the assessment is a trained health professional who assesses the following:

- level or types of support wanted and needed

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\*\* Whānau means family or an extended family or group of people who are important to a person who is receiving a service. Family includes a person's extended family and whānau, their partners, friends, guardian, or other representatives nominated by the person.

- involvement of family or whānau
- support received from health professionals, for example doctor, physiotherapist
- eligibility for support (community services card)
- cultural needs
- where to refer for more help, for example a more in-depth assessment with a specialist or therapist.

The first assessment can be carried out by telephone, a home visit or going to a NASC service. A telephone assessment lasts 20-30 minutes, with questions to determine the eligibility and needs of the person. In some instances, a telephone assessment is all that is required to develop a care plan or decide an action plan. A home visit assessment usually lasts 90-120 minutes. Assessments cover activities of daily living, medicines management, community supports, family or whānau involvement, pain assessments and level of depression, cultural preferences, house equipment needs or modifications. The NASC have language translators and Māori<sup>††</sup> needs assessors, should a person wish to have one present during the assessment. The NASC then coordinates the commencement of these services and supports. Support needs and support plans are monitored and reviewed by the home support service provider at least once a year or more frequently if deemed necessary. There is a strong emphasis on including family, whānau, and friends in home support throughout the assessment pathway including their feedback about the service, using a complaints and compliments system.<sup>(244, 248)</sup>

According to the Ministry of Health, waiting times for contact from NASC is one to three days from receipt of referral and 24 hours for urgent referrals. Less urgent needs assessments are usually carried out within twenty working days, with support services starting within ten working days after assessment. Lower priority needs may take up to six weeks to gain support services.

In addition, New Zealand has the Needs Assessment Service Coordination Association (NASCA) which is a national association for NASC managers and other senior NASC team members within the disability and health sectors. This association provides leadership and support to members in implementing partnership, participation and protection among service providers and people using services. Assessment of Needs services falls under the Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulations 1996.

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<sup>††</sup> Māori means race of people who have lived in New Zealand and the Cook Islands since before Europeans arrived.

In New Zealand, the International Resident Assessment Instrument (interRAI) is a suite of clinical assessment instruments used to assess an older person's care needs in the community. InterRAI is an internationally recognised and evidence-based assessment tool with its own designated website interRAI New Zealand. The assessment is carried out by a registered healthcare worker and includes an assessment of physical wellbeing, health conditions, activities, mood, medications, whether any directives have been set up for the future, and living circumstances. According to the Ministry of Health (2018), over 100,000 interRAI assessments are completed each year across New Zealand. Data retrieved from the assessments are also used as a source of information to inform health policies, healthcare professionals and researchers.<sup>(248, 249)</sup>

### **3.8.6 Funding and commissioning**

Home support services in New Zealand are funded by the Ministry of Health Disability Support Services, District Health Boards (DHBs) and Accident Compensation Corporation (ACC), or the Ministry for Social Development, depending on the needs of the person receiving home support. A report from the HCHA in 2019 claimed that 48% of people receiving HCSS are funded by DHBs through support for older people, 23% are funded by the Ministry of Health Disability Support Services and 29% of recipients are funded by ACC to support recovery from injury.<sup>(250)</sup> The option is also available to purchase services privately. According to the National Framework for HCSS (2020), over 75,000 older people received government-funded HCSS provided in their homes in New Zealand. DHBs funded HCSS at a cost of over \$478 million in 2017-2018.<sup>(245)</sup> Ministry of Health Disability Support Services, DHBs and ACC usually contract other professional organisations to provide home support services. Most home support service contracts are moving away from fixed tasks and hours to a more flexible approach.

HCSS are not commissioned under a national contract, so funding arrangements vary between the Ministry of Health, Accident Compensation Corporation and the 20 DHBs. The DHBs commission services and supports to meet the needs of the local population. However, this can vary in what and how the services are funded. Some DHBs adopt a fee for service or a bulk funding approach to service providers. DHBs also use a case-mix model to allocate resources but they are not consistent throughout New Zealand. The interRAI assessment instrument is used in some cases to form the basis for case-mix predictor selections. The New Zealand government is currently working on a single, nationally consistent case-mix method that is planned to be implemented across all DHBs by July 2022.<sup>(245)</sup>

The different funding schemes associated with the different levels of needs are outlined in this section under the following headings:

- people aged 65 years and over
- people with a physical, intellectual or sensory disability (or combination)
- people living with impairments caused by accident or injury.

### **People aged 65 years and over**

The DHBs funds HCCS for people aged 65 years and over. The local DHB firstly funds the Needs Assessment Service to undertake the assessment and establish the support plan. If home support is allocated, the DHB pays a provider organisation to provide the service. This includes disability support services for older people and those with mental health needs aged over 65 years. The Work and Income Department administers Community Service Cards on behalf of the Ministry of Health. New Zealanders can receive this card if they fit the eligibility criteria based on income and other set criteria. The Community Service Card can be used to fund household management supports such as preparing meals, washing clothes and house-cleaning. Personal care supports are funded by the local DHB and access to them does not require a community services card.<sup>(250, 251)</sup>

### **People with a physical, intellectual or sensory disability (or combination)**

The Ministry of Health Disability Support Services funds HCCS for people with a physical, intellectual or sensory disability. They firstly pay the Needs Assessment Service to work with the person with a disability to identify support needs, decide on eligibility and a support plan. Household management supports are funded through the Community Services Card. In addition, people with a disability have the option of applying for Individualised Funding (IF). This is a scheme where the person uses individualised funds to purchase household management and personal care. Support workers provide household management or personal care and can include family members, contracted personnel or organisations, and the person using the home support service can pay costs relating to the employment of support workers. The IF offers more autonomy and control over a person's supports and service delivery. However, this IF does not cover costs in relation to household equipment or modification requirements.<sup>(252)</sup>

## People living with impairments caused by accident or injury

People living with impairments caused by accident or injury can submit a claim for home support services to the ACC. A doctor or other healthcare provider must complete a referral form. If ACC accepts the claim and agrees to pay for home support, it allocates a 'package of care' or arranges a more detailed assessment for more complex cases. ACC will fund the home support provider organisation.

### 3.8.7 Workforce

Health Workforce New Zealand (HWNZ) has overall responsibility for planning and development of the health and disability workforce.<sup>(240)</sup> There are approximately 16,000 workers in the HCSS sector in New Zealand, with support workers making up the majority (86-95%) of the workforce. The Director-General's Reference Group for In-Between travel (2015) reported that the HCSS workforce had an older age profile, with 54% aged between 45-64 years and were predominantly female.<sup>(251)</sup> HCSS support workers are unregulated in New Zealand but are accountable under the Health and Disability Commissioner Act 1994 and must adhere to the Code of Health and Disability Services Consumers' Rights.

The Care and Support Workers (Pay Equity) Settlement Act 2017 was enacted following increased pressures on the government to address the many workforce challenges experienced within the sector. The Director-General's Reference Group (2015) reported that the current workforce situation was not sustainable for the future and highlighted that turnover of the HCSS workforce was estimated at approximately 25-30%, with 50% turnover in the first year of employment. This high turnover resulted in increased pressures on service providers to train new staff and reduced abilities to train more experienced staff and thus significantly impacted training budgets. This high turnover was most likely due to low wages that do not recognise training or qualifications, along with poor working conditions.<sup>(251)</sup> Subsequently, the Care and Support Workers (Pay Equity) Settlement Act 2017 resulted in many changes for care and support workers in New Zealand's home and community support services. For example, changes included: an increase in salaries; salaries are now based on level of qualifications or length of service; embedding a principle of valuing and recognising the commitments of the support workers in their role; and placing an emphasis on training this workforce and providing opportunities to achieve nationally recognised qualifications.<sup>(253)</sup> Despite the legislative enactment in response to a strong recommendation on 'regularisation' of the HCSS workforce<sup>(251)</sup>, the Health and Disability Review (2020) commented on the HCSS services being still carried out by a "semi-trained workforce with low wages, low qualification levels and poor working conditions."<sup>(254)</sup> Conversely, an analysis of data

collected in 2017-2018 and 2019 on care and support workers identified a significant increase in support workers with qualifications in the home and community support, disability, and mental health and addiction sectors. Support workers with higher qualifications deliver more hours of care than unqualified workers.<sup>(39)</sup>

Careerforce is a government appointed organisation in New Zealand that supports training and provides skill standards and nationally recognised qualifications across the health and well-being sector. Training is offered for home and community support workers from entry level through to advanced specialist. There is a designated section in Careerforce specific to home and community services courses and training. The qualifications for training specific to home support workers adapted from Careerforce are presented in table 3.9.

**Table 3.9: Qualification levels for Home Support Workers adapted from Careerforce**

New Zealand Certificate in Health and Wellbeing	Description	Length of time
Level 2 (40-41 credits)	Induction programme to develop entry-level skills and knowledge	7 months
Level 3 (70 credits)	This programme aims to develop the skills and knowledge required to support and empower people in home and community settings.	12 months
Level 4-Advanced Support (70 credits)	This programme aims to develop the skills and knowledge required to support and empower people with complex needs and/or requiring advanced dementia care or palliative care. It also benefits those who lead a team.	12 months

**Source:** Careerforce (2021). Home and community services courses and training<sup>(255)</sup>

### 3.8.8 Legislation

This section describes key legislation in New Zealand that applies to home support services. The New Zealand health and disability system's statutory framework is made up of over 20 pieces of legislation. The most significant are:

- Health Act 1956
- New Zealand Public Health and Disability Act 2000
- Health and Disability Services (Safety) Act 2001

- Crown Entities Act 2004
- Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulations 1996.

### **3.8.8.1 Health Act 1956**

The Health Act 1956 sets out the roles and responsibilities of individuals to safeguard public health, including government organisations and personnel, for example the Minister of Health, the Director of Public Health, and designated officers for public health. The Act sets out the functions of the Ministry of Health and local authorities in improving, promoting and protecting public health. Public health provisions include environmental health, infectious diseases, health emergencies, and the national cervical screening programme.<sup>(256)</sup>

### **3.8.8.2 New Zealand Public Health and Disability Act 2000**

The New Zealand Public Health and Disability Act 2000 established new publicly-owned health and disability organisations, such as District Health Boards, and sets out the duties and roles of key organisations, including the promotion of integrating all health services, especially primary and secondary services. In addition, structures underpinning public sector funding were established. The Act also sets the strategic direction and goals for health and disability services in New Zealand. Such goals include improving and reducing disparities in health and disability outcomes for all population groups in New Zealand. Objectives are set out as to provide a community voice in personal health, public health, and disability support services and to facilitate access to, and the dissemination of information for, the delivery of these services.<sup>(249)</sup>

### **3.8.8.3 Health and Disability Services (Safety) Act 2001**

The Health and Disability Services (Safety) Act 2001 is the legislation that underpins the certification of health care services in New Zealand. The Act places a duty on health and disability service providers to take responsibility in providing safe services and to continuously improve the quality of service provision. Setting standards and certification of services against the standards are clearly described in this legislation. Section 5 of the Act lists and defines services to which the legislation applies to, however it does not explicitly state home support services, but rather includes a service as one that is 'provided to people with disabilities or people who are frail (whether because of their age or for some other reason), for their care or support or to promote their independence.' Service standards are described as standards that can be practically applied in health and disability services and should be reviewed at least every four years.

Section 21 of the Act describes the content of the standards, for example standards should have 'statements of appropriate care delivery outcomes for providers of health or disability services of any kind' and 'statements of appropriate care delivery outcomes for particular aspects of providing health or disability services of any kind.' In addition, such statements may include means of achieving the outcomes and or criteria for assessing whether the outcomes are appropriate. Health and disability standards must be reviewed regularly and approved by the Minister of Health.<sup>(93)</sup>

#### **3.8.8.4 Crown Entities Act 2004**

The Crown Entities Act 2004 sets out the provisions for the establishment, governance, and operation of Crown entities. Crown entities are organisations that form part of New Zealand's state sector and those listed in the Act that are applicable to home support services include Health Quality and Safety Commission, Health and Disability Commissioner, and Mental Health Commission.<sup>(25)</sup> The Act clarifies accountability relationships and reporting requirements between Crown entities, their board members, responsible Ministers, and the House of Representatives.

#### **3.8.8.5 Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulations 1996**

The Code of Health and Disability Services Consumers' Rights was enacted into law in 1996 under the Health and Disability Commissioner Act 1994. This Code establishes a number of rights for consumers of health and disability services in New Zealand. Subsequently, it places a duty on providers of health and disability services to comply with the Code. As such, home support services fall under the remit of this Code. The Code of Health and Disability Services Consumers' Rights consists of ten rights and are set out in table 3.10. The Health and Disability Commissioner investigates complaints, along with health practitioners' professional bodies pertaining to a breach of this Code.<sup>(257)</sup>

**Table 3.10: The Code of Health and Disability Services Consumers' Rights (1996)**

<b>Consumers' Rights</b>	<b>Description</b>
Right 1	The right to be treated with respect.
Right 2	The right to freedom from discrimination, coercion, harassment, and exploitation.

Right 3	The right to dignity and independence.
Right 4	The right to services of an appropriate standard.
Right 5	The right to effective communication.
Right 6	The right to be fully informed.
Right 7	The right to make an informed choice and give informed consent.
Right 8	The right to support.
Right 9	Rights in respect of teaching or research.
Right 10	The right to complain.

**Source:** The Health and Disability Commissioner NZ (1996). The Code of Health and Disability Services Consumers' Rights.<sup>(257)</sup>

### 3.8.9 Regulation

New Zealand does not have a legislative regulatory framework or requirements for home support services. However, HCSS providers that hold a contract with the Ministry of Health, a District Health Board and or the Accident Compensation Corporation must be certified against the *Ngā Paerewa Health and Disability Services Standard NZS 8134:2021* which came into effect on 1 March 2022. Prior to this date, providers were certified against the *Home and Community Support Sector Standard NZS 8158:2012*. This section describes the two key organisations and their duties that govern the certification of HCSS in New Zealand. The key organisations are:

- Conformity Assessment Bodies
- HealthCERT.

#### 3.8.9.1 Conformity Assessment Bodies

In New Zealand, conformity assessment bodies, also referred to as designated auditing agencies (DAAs) audit HCSS providers. The HCSS providers must demonstrate that they are complying with the *Ngā Paerewa Health and Disability Services Standard NZS 8134:2021* through this audit process in order to obtain certification. In addition, providers of home support services must pay for these certification audits. The DAAs are responsible for meeting their own requirements and criteria under the International Standardisation Organisation, third party

international accreditation criteria and the New Zealand Health and Disability Services (Safety) Act 2001. The Ministry of Health requires that auditing practices are underpinned by the following principles:

- consumer focus
- outcome focus
- systems and process focus
- openness and transparency.<sup>(258)</sup>

There are three types of audits conducted:

1. certification audit valid for 3 years
2. verification audit (expanding service or change in service site, three years valid or alters existing certificate)
3. surveillance audit (monitoring that occurs within the period of certification).<sup>(258)</sup>

The audits comprise of a review of consumer records and then interviews with these consumers. The number of consumers interviewed depends on the size, nature, complexity, internal quality monitoring of consumer satisfaction and funding arrangements of the provider. Interviews can be face-to-face, telephone or surveys. Interviews are carried out with service providers, staff, and consumers and can be Māori or funder-focused interviews. The auditor determines the level of attainment the provider achieves for each criteria that is associated with each standard statement. A risk management matrix is also used if an audit result for any criterion is partially attained or unattained. Results or findings are actioned in line with this risk matrix.<sup>(258)</sup> The levels of attainment are described as follows:

- **Continuous improvement:** The service has attained the criterion and demonstrates a review process, including:
  - analysing and reporting findings
  - having evidence that it has taken action based on those findings
  - improving service provision and consumers' safety or satisfaction as a result of the review process.
- **Fully attained:** The service demonstrates implementation (for example, practice evidence, training, records or visual evidence) of the process, systems or structures to meet the required outcome of the criterion.
- **Partially attained:** There is evidence that the service has implemented an appropriate process (for example, a policy, procedure or guideline), system or structure without having the required supporting documentation,  
Or

A documented process (for example, a policy, procedure or guideline), system or structure is evident, but the organisation or service cannot demonstrate that it has implemented it where this is required.

- **Unattained:** The organisation or service cannot demonstrate appropriate processes, systems or structures to meet the required outcome of the criterion.
- **Not applicable:** The criterion does not apply to the service that is being audited.<sup>(258)</sup>

A rigorous certification decision process takes place over two stages. This entails an experienced auditor of home support services conducting a systematic peer review of the audit report, including a review of field notes, workbooks and tools. The peer reviewer must be independent of the original audit. A recommendation is then made to certify or delay certification. An independent assessment committee made up of two personnel conduct an independent review of the audit reports and decide the final decision on awarding certification. The certification period is three years from the date of the certification decision. A service provider must have at least one on-site surveillance audit during the mid-point of the certification period.<sup>(258)</sup>

In some cases, providers were certified against the *Health and Disability Services Standard (HDSS 8134:2008)*. This standard has been replaced with the recently published *Ngā Paerewa Health and Disability Services Standard (NZS 8134:2021)*. Providers are expected to include additional evidence of implementation of standards relevant to home and community support services. These cases include; home and community support services that are provided as part of a larger organisation's services and that larger organisation was certified against the *Health and Disability Services Standard (HDSS 8134:2008)* and the provider uses the same management, quality and risk management systems across its organisation, and home and community support services can be identified within these management, quality and risk management systems.

### 3.8.9.2 HealthCERT

HealthCERT is the government organisation with responsibility to issue certificates, review audit reports and manage legal issues. They coordinate and administer the HCSS framework. HealthCERT's role in relation to home support services and certification is to maintain a central repository and collation point for audit reports, audit summaries and progress reports for corrective actions. The department manages audit reports, the web page for publishing audit summaries and provides communication links between relevant organisations, for example Conformity Assessment Bodies.

### **3.8.10 Standards, guidance, policies, frameworks and strategies**

This section describes the Home and Community Support Sector Standard used for the inspection, monitoring and certification of home support services in New Zealand. In addition, guidance documents, for example sector solutions, guidelines and frameworks have been developed to support the implementation of the Standard and will be discussed in section 3.8.11. The strategic context that underpins how HCSS operates across New Zealand will be discussed in section 3.8.12.

#### **3.8.10.1 Standards**

Standards New Zealand is a business unit of the Ministry of Business, Innovation and Employment and has responsibilities in developing and publishing Standards in New Zealand. Standards New Zealand has recently developed and published the *Ngā Paerewa Health and Disability Services Standard NZS 8134:2021* that superseded the following health care services standards:

- Health and Disability Services Standard (NZS 8134:2008)
- Fertility Services Standard (NZS8181:2007)
- Home and Community Sector Standard (NZS 8158:2012)
- Interim Standard for Abortion Services in New Zealand.

The combination of the above health and disability standards is planned to reduce duplication across the standards. This section will firstly describe the recently published *Ngā Paerewa Health and Disability Services Standard NZS 8134:2021* and then briefly summarise the *Home and Community Sector Standard (NZS 8158:2012)* as this standard was still in effect up until 28 February 2022.

#### **Ngā Paerewa Health and Disability Services Standard (NZS 8134:2021)**

The health and disability services standards were revised as part of a programme to ensure consistency with Te Tiriti o Waitangi<sup>‡‡</sup> obligations and consumer rights and provider obligations under the Code of Health and Disability Services Consumers' Rights in New Zealand. This means that every service and every person responsible for implementing the health and disability standard should be cognisant of the Te Tiriti, the Code of Health and Disability Services Consumers' Rights, and the United

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<sup>‡‡</sup> Te Tiriti o Waitangi means Treaty of Waitangi and underpins the relationship between the Government and Māori. It is based on the three "P's", as they are often referred to, which are the principles of partnership, participation and protection.

Nations instruments agreed to by New Zealand, and comply with the duties set out in them. Subsequently, the revised health and disability services standard (NZS 8134:2021) represents high level overarching outcome criteria that reflect a more person and whānau-centred health and disability service.<sup>(259)</sup> There are five key principles underpinning the standard. They are as follows:

- achieving Māori health equity
- accessible health and disability services
- partners with choice and control
- best practice through collaboration
- standards that increase positive life outcomes.<sup>(260)</sup>

The standard applies to health and disability service providers in both public and private settings. Health and disability services that are required to be certified under the Health and Disability Services (Safety) Act 2001 must comply with all relevant criteria. Not all criteria within the standard (NZS 8134:2021) are relevant to all services. The *Health and Disability Services Standard (NZS 8134)* consists of six sections that are divided into subsections, with each subsection having a number of criteria. The title of each section is:

1. Our rights
2. Workforce and structure
3. Pathways to wellbeing
4. Person-centred and safe environment
5. Infection prevention and antimicrobial stewardship
6. Restraint and seclusion.<sup>(259)</sup>

Each section begins with an outcome statement, followed by the subsection title that outlines what this means to the person using the service in terms of expectations from the services and support they receive. In addition, there is a statement outlining what service providers will do to deliver best practice and quality care to people using the service relating to the subsection title. This includes outcome statements from: the person using the services referred to as 'the people' statement; Māori using the services referred to as 'Te Tiriti'§§ statement; and the service provider referred to as 'service providers' statement. The criteria then sets out in more detail the approach to compliance with the section statements. Not all criteria will be applicable to home support services, for example criteria describing

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§§ Te Tiriti refers to the Te Tiriti o Waitangi and means Treaty of Waitangi and underpins the relationship between the Government and Māori. It is based on the three "Ps", as they are often referred to, which are the principles of partnership, participation and protection.

the physical environment where care is provided.<sup>(259)</sup> Table 3.11 displays an example that describes a section, sub-section and criteria adapted from the *Health and Disability Services Standard (NZS 8134:2021)* document.

**Table 3.11: Section 4: 4.2, Criteria 4.2.3, 4.2.6 adapted from Health and Disability Services Standard (NZS 8134:2021)**

<b>Section 4: Person-centred and safe environment</b>		
Outcome statement: Person-centred and safe environment. Health and disability services are provided in a safe environment appropriate to the age and needs of the people receiving services that facilitates independence and meets the needs of people with disabilities.		
<b>4.2: Security of people and workforce</b>		
I know what it means for me:		
<i>The people</i> I trust that if there is an emergency, my service provider will ensure I am safe.	<i>Te Tiriti</i> Service providers provide quality information on emergency and security arrangements to Māori and whānau.	<i>As service providers</i> We deliver care and support in a planned and safe way, including during an emergency or unexpected event.
<b>Criteria</b>		
4.2.3: Healthcare and support workers shall receive appropriate information, training, and equipment to respond to identified emergency and security situations. This shall include fire safety and emergency procedures.		
4.2.6: Service providers shall identify and implement appropriate security arrangements relevant to the people using services and the setting, including appropriate identification.		

**Source:** Standards New Zealand (2021). Health and Disability Services Standard (NZS 8134:2021)<sup>(259)</sup>

### **Home and Community Sector Standard (NZS 8158:2012)**

*Home and Community Sector Standard (NZS 8158:2012)* sets out what people receiving support in a home or community setting can expect from the services they receive and the minimum requirements to be attained by organisations. The scope of the Standard covered all home and community support services provided in a person's home or in their community. It applied to organisations and service providers who are either publicly or privately contracted to provide home and community support. These organisations and service providers are those that provide:

- personal care and household management

- developing, maintaining, or restoring daily living skills to maximise independence and participation in valued social roles
- access to social services and participation in community activities.<sup>(261)</sup>

Organisations and service providers that were excluded from the Standard are:

- Services provided by registered health practitioners working in the capacity of their registration but who are not employed or contracted by organisations subject to the Standard
- Certified health and disability services that are subject to *Health and Disability Services Standard (NZS 8134:2021)*, and are not providing home and community services, separate to disability services that they provide
- Family and whānau\*\*\* members who are not employed by an organisation.<sup>(261)</sup>

The standard was applicable to people of any age who were receiving long-term support, short-term support or palliative care. They set out what people using home and community support services should expect from the service and ensured that services were assessed on outcomes achieved for people using the service. The standard helped service providers to comply with the obligations set out in the Code of Health and Disability Services Consumers' Rights (1996).

### **3.8.10.2 Guidance**

This section will describe some guidance documents that have been published to support the implementation of the *Health and Disability Services Standard (NZS 8134:2021)* in providing a safe and quality home support service. These will be discussed under sector guidance, medication guidelines and a National Framework for Home and Community Support Services.

### **Sector Guidance for Ngā Paerewa Health and Disability Services Standard (NZS 8134:2021)**

In addition to developing a new Standard for health and disability services, Standards New Zealand and the Ministry of Health have developed 'Sector Guidance.' Sector guidance are service-specific guidance on how the criteria described in the standard can be interpreted and met. The sector guidance is not

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\*\*\* Whānau means family or an extended family or group of people who are important to a person who is receiving a service. Family includes a person's extended family and whānau, their partners, friends, guardian, or other representatives nominated by the person.

mandatory and serves as a guide to assist service providers.<sup>(260)</sup> Table 3.12 presents an example of the sector guidance to explain what they look like.

**Table 3.12: An example adapted from Sector Guidance for Ngā Paerewa Health and Disability Services Standard (NZS 8134:2021)**

Criteria	Guidance	Who the sector guidance are for				
		Aged care	Fertility services	Home and community	Residential disability	Hospice
4.2.1: Where required by legislation, there shall be a Fire and Emergency New Zealand approved evacuation plan.	Service providers meet the reporting requirements of the New Zealand Fire Service as specified in the Fire and Emergency New Zealand (Fire Safety, Evacuation Procedures, and Evacuation Schemes) Regulations 2018.	✓	✓		✓	✓
4.2.3: Healthcare and support workers shall receive appropriate information, training, and equipment to respond to identified emergency and security situations. This shall include fire safety and emergency procedures.	<p>Service providers consider civil defence requirements, noting a generator is not always available.</p> <p>There is business continuity planning or a disaster recovery plan in place. The service provider has evidence it has been trialled.</p> <p>Service providers provide induction and training for health care and support workers around responding to emergency and security situations.</p> <p>Service providers monitor the wellbeing of their health care and support workforce during an emergency.</p> <p>Selected health care and support workers undertake fire warden training.</p> <p>Service providers support people receiving services to maintain their own wellbeing and know what to do in an emergency.</p>	✓	✓	✓	✓	✓

**Source:** Standards New Zealand (2021). Sector Guidance for Ngā Paerewa Health and Disability Services Standard (NZS 8134:2021).<sup>(260)</sup>

## **Medication Guidelines for the Home and Community Support Services Sector**

In response to recommendations of a review of medication management and home support workers commissioned by the Home and Community Health Association in 2016, the Medication Guidelines for the Home and Community Support Services Sector were developed. These guidelines serve to complement the *Home and Community Support Sector Standard (NZS 8158:2012)* and the *Ngā Paerewa Health and Disability Services Standard (NZS 8134:2021)*, and are based on evidence of best practice and relevant legislation. They are a guide for service providers to support safe medication practice, policies and processes for people at home. The guidelines reflect a comprehensive guide for service providers and staff on: roles and responsibilities; medication competency assessment; documentation including reporting of medication errors and adverse reactions; high-risk medications and controlled drugs; non-pre-packed medications; and supply, checking, storage and returns.<sup>(262)</sup> It is the responsibility of the service provider to develop their own policies and processes, to ensure adequate education and training and develop medication competency assessment, appropriate to their specific services. In addition, home support workers should receive appropriate training to meet the needs of the person they are providing care and support to, according to individual support plans.<sup>(262)</sup>

## **The National Framework for Home and Community Support Services**

The National Framework for Home and Community Support Services was developed in response to the New Zealand Healthy Ageing Strategy (2016)<sup>(263)</sup> and the Director-General's Reference Group (DGRG) report on in-between travel (2015)<sup>(251)</sup> to address the multiple and increasing demands on HCSS. The framework provides guidance to district health boards for future commissioning, developing, delivering and evaluating HCSS to improve national consistency and quality of care. It is planned for full implementation by 2022. The scope of the National Framework for Home and Community Support Services is clearly set out as one that intends to:

Develop a national framework for sustainable future models of care for publicly funded home and community support services (HCSS) that support older people to live well, get well, and stay well closer to home.<sup>(39)</sup>

The framework is applicable to DHB-funded services for:

- People aged 65 years and over who have an assessed need following the interRAI assessment and meet criteria for funding
- People considered to be alike in age and interest, for example, Pacific peoples and Māori, aged over 55 years, and others aged over 60 years, with age-related disabilities
- Older people receiving HCSS who require increased support following an acute health episode who have required hospitalisation
- HCSS that may continue concurrently with short-term Accident Compensation Corporation (ACC) services.<sup>(39)</sup>

The framework sets out the key ingredients to a successful HCSS model of care and support. These comprise: addressing inconsistency of services across New Zealand; responding to more complex needs of an ageing and diverse population; changing models of care; self-management; technology; a changing workforce; and the HCSS market. Similar to the revised Health and disability services draft standard, the framework builds on the obligations of Te Tiriti o Waitangi in improving health outcomes for all. This is embedded in the framework's vision and principles. The vision for home and community support services in New Zealand is described as:

High-quality services that flexibly meet the needs of individuals, are person, family and whānau-focused and culturally appropriate, are sustainable over time, and are delivered by a competent, skilled, well-trained workforce.<sup>(39)</sup>

The key principles underpinning the framework are:

- Person-directed
- Connected
- High Quality and safe
- Flexible
- Equitable
- Responsive to Māori
- Cost effective and sustainable.

In addition, the framework outlines nine core components of how HCSS should be provided and nationally monitored. These are: nationally consistent assessments; support planning; enabling focus; integrated; competent and supported workforce; clinical oversight; optimum use of natural supports; culturally competent; and performance focused. They include a list of outcome measures and indicators for monitoring quality improvements in the HCSS.<sup>(39)</sup>

### 3.8.10.3 Strategies

There are four key strategies in place that are applicable to home support services in New Zealand. This section will give a brief summary of these strategies.

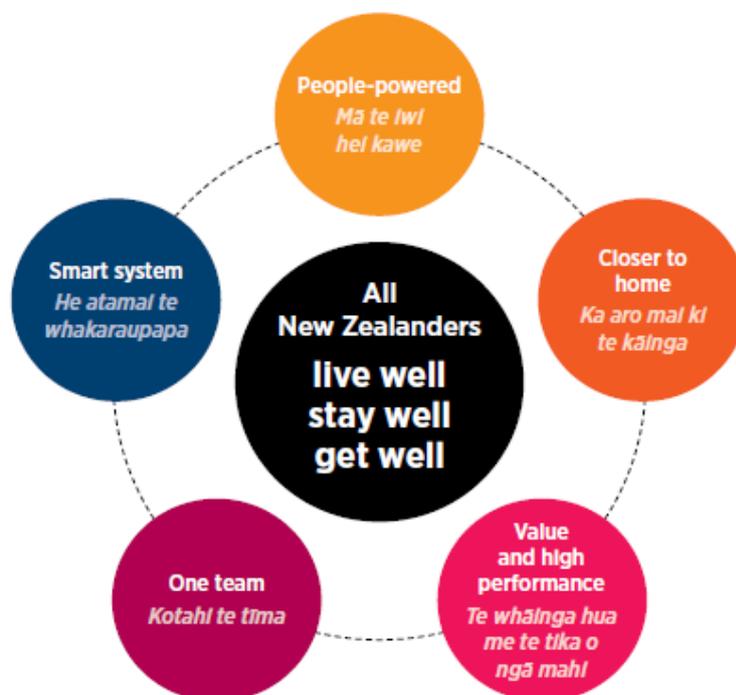
#### New Zealand Health Strategy 2016

The New Zealand Health Strategy 2016 was informed by government programmes, initiatives and stakeholder engagements, including public consultations and independent reports. The strategy is made up of two documents entitled *Future Direction*<sup>(264)</sup> and *Roadmap of Actions 2016*<sup>(265)</sup> which intend to guide a future direction for health services and improve the health of New Zealanders and their communities. The strategy highlights the challenges and opportunities that the health system faces and is guided by five strategic themes (Figure 3.6) with an overall aim that:

**All New Zealanders live well, stay well, get well**, in a system that is **people-powered**, provides services **closer to home**, is designed for **value and high performance**, and works as **one team** in a **smart system**.

This strategy has a population focus and aims for a fair and responsive health system that improves health outcomes for all population groups in New Zealand. In order to do this, the health system needs to improve its understanding of different population groups, involve people in designing services and provide a range of services that is appropriate for the people who use them. Emphasis is placed on supporting a person's health close to home and having timely and equitable access to wellness and treatment services.<sup>(264)</sup>

**Figure 3.6: Five Strategic themes of the New Zealand Health Strategy 2016**



**Source:** NZ Ministry of Health (2016). The New Zealand Health Strategy.<sup>(264)</sup>

### **New Zealand Disability Strategy 2016-2026**

The New Zealand Disability Strategy 2016-2026 was informed by extensive engagement with people with disabilities and acts as a guide to government organisations on issues relating to disability over a ten-year cycle. The main focus is giving children and adults with a disability greater autonomy over their care and support. It centres on a vision that New Zealand is 'a non-disabling society' and incorporates the principles set out under Te Tiriti o Waitangi, the United Nations Convention on the Rights of Persons with Disabilities (the Convention) and ensuring that people with a disability are involved in decision-making that impacts them.<sup>(266)</sup> The strategy describes eight outcomes that will achieve this vision and are listed below:

1. Outcome 1 – education
2. Outcome 2 – employment and economic security
3. Outcome 3 – health and wellbeing
4. Outcome 4 – rights protection and justice
5. Outcome 5 – accessibility

6. Outcome 6 – attitudes
7. Outcome 7 – choice and control
8. Outcome 8 – leadership.<sup>(266)</sup>

## Healthy Ageing Strategy 2016

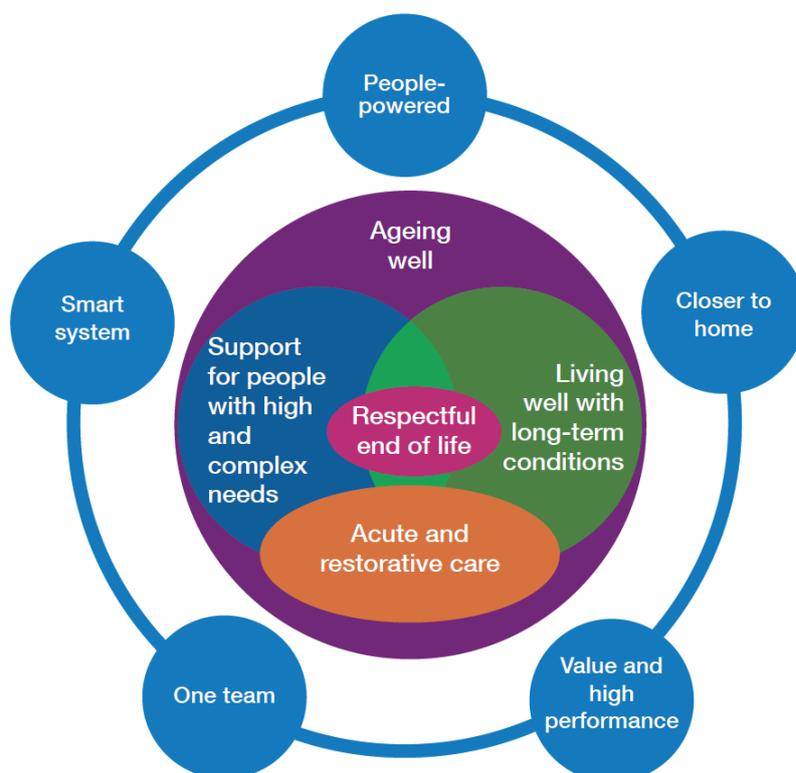
The Healthy Ageing Strategy 2016 sets out a framework and future action plans for the health and wellbeing of older people in New Zealand over ten years. It was developed for older people, their families and their communities and builds on the New Zealand Health Strategy 2016 and is informed by the New Zealand Disability Strategy 2016. The vision for this strategy is that:

Older people live well, age well and have a respectful end of life in age-friendly communities.<sup>(263)</sup>

The strategy describes how this vision can be achieved through five outcome areas. The five outcome areas form the framework for the strategy and involve New Zealand's policies, funding, planning and service delivery and are listed below:

- Prioritise healthy ageing and resilience throughout people's older years
- Enable high-quality acute and restorative care, for effective rehabilitation, recovery and restoration after acute events
- Ensure older people can live well with long-term conditions
- Better support older people with high and complex needs
- Provide respectful end-of-life care that caters to personal, cultural and spiritual needs.<sup>(263)</sup>

The outcomes are interlinked with the five themes of the New Zealand Health Strategy 2016 as displayed in figure 3.6. Overall the strategy recognises New Zealand's ageing population, diverse ethnic population groups, growing rates of long-term chronic health conditions, and disabilities that require support on a daily or regular basis. It has a strong focus on prevention, wellness and supporting independence. In doing so, it places an emphasis on prioritising equitable home and community support services that are appropriate to older people's needs and preferences. In addition, better integration of services to support older people and effective management of workforce and technology should be in place.

**Figure 3.7: Strategic Framework for Healthy Ageing**

**Source:** NZ Ministry of Health (2016). Healthy Ageing Strategy.<sup>(263)</sup>

### 3.8.11 Findings from reviews

There are a number of key documents that examine and review home support services in New Zealand. A summary of these documents are outlined in the following section.

#### 3.8.11.1 The Health and Disability System Review 2020

*The Health and Disability System Review 2020* was commissioned by the Minister of Health in 2018 and is a large and comprehensive examination of the Health and Disability system in New Zealand. It was conducted by an expert panel, with an aim to develop recommendations to change the health and disability system in New Zealand to one that delivers wellness, access, equity, and sustainability for all New Zealanders. The recommendations mainly focus on system-level change ranging from legislation, structural and cultural changes. An emphasis is placed on improving population health outcomes and the review recognises the value of communities in population health and designing services that address the needs of all New Zealanders. In particular, it highlights the variability in home support for people with

disabilities regarding planning, funding, and provision of services. It recommends that an assessment of need should be in place for people with disabilities, as opposed to eligibility being based on diagnosis.<sup>(254)</sup> The main points of recommendations that are currently with the Ministry of Health include the following:

- The establishment of a new organisation called *Health New Zealand*, with responsibilities for: leading the delivery of health and disability services; providing consistent operational policies; ensuring clinical and financial improvements; and developing a commissioning framework
- The establishment of a new organisation called *Māori Health Authority*, an independent departmental body who will report directly to the Minister of Health with responsibility for: Māori health policy; monitoring of system performances regarding Māori health outcomes and equity; and meeting the needs of Māori people
- The reduction of DHBs from 20 to between eight to 10 over the next five years. DHBs should take on full accountability for: achieving equitable health outcomes; ensuring services are planned and delivered appropriate to their communities; and strategic planning for community engagements focusing on population health outcomes
- Better leadership and integration between hospitals and community services
- The Ministry of Health should lead; a sector-wide workforce strategy collaborating with Māori Health Authority and Health NZ; priority for digital investments and data collections to increase interoperability between services.<sup>(254)</sup>

### **3.8.11.2 The Home and Community Health Association Briefing for Incoming Ministers (2020)**

The Home and Community Health Association (HCHA), the representative group for providers of home and community health services in New Zealand submitted a briefing document to the Ministry of Health in response to the Health and Disability System Review 2020. This document outlines the challenges within the home and community support sector. Challenges that are reported pertain largely to a lack of standardisation in funding models and service provisions across the DHBs. The document stresses that these challenges are creating variations in equitable access and quality of care across services. Subsequently, admissions to residential care settings and hospitals are rising and thus, goes against the purpose of home and community support services. The HCHA suggest working with the New Zealand government to develop an integrated and partnership approach to the HCSS, with emphasis on an improved model of care, funding, training and securing workforce, and developing more options for Māori people.<sup>(241)</sup>

### **3.8.11.3 Recognising the Contribution of the Home and Community Support Sector to New Zealand 2019**

*Recognising the Contribution of the Home and Community Support Sector to New Zealand 2019* is a report that describes home and community support across New Zealand in terms of its impact on the New Zealand health system and its future potential. The report was conducted on behalf of the HCHA and is informed by best practice reviews, current state assessments, stakeholder workshops, and primary and secondary analysis of both publicly available interRAI assessment data, and data made available by a DHB. The report consists of the following sections:

- section 1 - A profile of the HCSS sector
- section 2 - Key challenges facing the HCSS sector
- section 3 - A possible future state for the HCSS sector
- section 4 - Demonstrating the strategic opportunity for the HCSS sector
- section 5 - Recommendations and next steps.<sup>(250)</sup>

It highlights similar challenges to those identified in other reports or reviews, including population demands, variations in funding models and accessibility to HCSS, workforce characteristics and fragmented care for people using the services. The report uses case studies as illustrations of a person's journey throughout the health and social care system to highlight the benefits of a person-centred and integrated care model that is better coordinated and flexible to the needs of the person using the service. The report recommends the analysis of older people's experiences of their care and support, appropriate monitoring and evaluation mechanisms, building partnerships with key system stakeholder groups and adoption of advanced technologies.<sup>(250)</sup>

### **3.8.11.4 Towards Better Home and Community Support Services for all New Zealanders, Advice to the Director-General of Health from the Director-General's Reference Group for In-Between travel (2015)**

The *Director-General's Reference Group (DGRG) report on in-between travel (2015)* is a review of the HCSS conducted as part of the implementation of the 'in-between' travel settlement agreement. The travel settlement agreement was in collaboration with HCSS providers, workers, unions, DHBs and the New Zealand government to resolve issues on workforce salaries. It was agreed to pay workers for time spent travelling between clients' homes and travel mileage. The review acknowledges the important role that the home and community services play in the overall health and disability sector. The reports highlights the barriers to developing services in HCSS

and have called for new ways of working to respond to the multiple and growing demands on HCSS. The DGRG report identified the following as key issues facing HCSS in New Zealand:

- increasing demands of people needing care and the complexity of care needed
- a lack of a nationally consistent approach to service delivery in response to community demands
- funding arrangements are not focused on the person at the centre
- a fragmented, semi-trained, poorly paid workforce resulting in high turnover
- increased demands on increasing skills and competencies for support workers to meet complex needs of persons using the service
- variation in contract agreements and funding resulting in insufficiencies in meeting growing demands of sector.<sup>(251)</sup>

There is a strong recommendation for the 'regularisation' of the HCSS workforce to sustain the HCSS sector and result in improved quality of service delivery.

Regularisation of workforce is described as a situation where workers have guaranteed hours, workloads and are paid a wage as opposed to situations where hours and wages are determined by the client's needs.<sup>(251)</sup> The report lists the benefits to regularisation of the workforce as follows:

- Increased quality and consistency of services delivered to people using the service
- Increased worker capability to respond to needs of the person using the service
- Creates a security and safety network for workers including greater certainty of employment and income, support for training, recognition of training for workers, better career pathway for support workers
- Enhanced provider capacity so can recruit and retain their workforce, be responsive to changing needs of people using their service
- Increased consistency and transparency in funding arrangements to meet service delivery needs.<sup>(251)</sup>

### **3.8.12 Summary and Lessons for Ireland**

In New Zealand, home support services are publicly funded and provided by service providers under contracts with government organisations. Home support services are determined by an assessment of need and eligibility criteria. The delivery of home support is governed and protected by the Code of Health and Disability Services Consumers' Rights (1996) and a certification process that is set out in national

legislation. A lesson that can be drawn from New Zealand is the government's commitment to provide health and disability services that are equitable and accessible to all New Zealanders. New Zealand has a diverse ethnic population and has experienced inequalities in health outcomes for sub-groups of the population. A strong theme across the New Zealand literature is a population focus that is based on a person-centred approach and includes partnerships with population sub-groups in its health system.

The Ministry of Health and Standards New Zealand have recently developed and published a revised health and disability services Standard. This standard is applicable to home support services in New Zealand. The standard development process was led by subject matter experts, was comprehensive and included extensive stakeholder engagement. Subsequently, experiences and information on up-to-date best evidence from New Zealand can contribute to developing National Standards on home support in Ireland. In addition, Standards developed for the health and disability sector are similar to Ireland's National Standards in that they comprise of outcome statements describing what a person using the service should expect from the service. Outcomes achieved form an integral part of the assessment of services. Sector Guidance has also been developed in New Zealand to complement the health and disability services Standard. The sector guidance intends to guide service providers on how to comply with the standard statements and associated criteria. In addition, New Zealand has *Medication Guidelines for the Home and Community Support Services Sector* that provides explicit explanations of roles and responsibilities and scope of practice for home support workers and healthcare professionals. Given the high-risk nature of medicines management and home support work being largely unsupervised, medicines management guidelines are essential in achieving patient safety. Ireland can learn from implementation strategies such as sector guidance and medicines management guidelines by adopting similar approaches that will act as enablers to: implementing National Standards; supporting service providers and care workers; and promoting patient safety.

In New Zealand, older people are assessed for home support needs using the interRAI instrument. This instrument has many functions. Firstly, it is comprehensive and examines many aspects of the older person, ranging from mood to advanced directives. It is internationally recognised and evidence based. In addition, New Zealand uses data from the interRAI to inform health policies and research. For example, New Zealand is planning to introduce a national case-mix method for the commissioning of home support services and the interRAI instrument can be used to inform case-mix predictors. Ireland can learn from the interRAI in adopting a standardised instrument developed from best evidence to support consistency in the

assessment of need and a person-centred approach for all people using home support services. In addition, adopting a tool such as the interRAI may act as a source of data collection for the Irish health system similar to New Zealand.

Ireland can also learn from the challenges experienced from the HCSS sector in New Zealand. New Zealand have had challenges pertaining to variations in funding models and workforce development. New Zealand's plans to introduce a national case-mix method for the commissioning of home support services will address inconsistencies in funding across organisations. This method will provide a more flexible approach and remove a time and task model of care delivery and thus, promote person-centred care. Workforce challenges include high turnover of staff, low salaries and a lack of recognition for skills and qualifications for social care workers. The New Zealand government have enacted legislation, The Care and Support Workers (Pay Equity) Settlement Act 2017, in order to address these challenges and have placed duties on the sector to value workers as a central part of the health system. The legislation has led to reviews of education and training, nationally recognised qualifications, and salary increases, with more secure working arrangements. This legislation followed on from a Settlement Agreement for In-Between Travel in 2014 that involved agreement between HCSS providers, workers, unions, DHBs and government to pay workers for travel mileage and time spent travelling between clients' homes. In addition, this agreement acted as a catalyst in regularising the HCSS workforce and enacting national legislation to protect the workforce and provide guaranteed wages.

## **3.9 Australia**

### **3.9.1 Overview of home support services**

Home support services in Australia are provided to all people who need them, as determined by a standardised care needs assessment, on an income-tested basis.<sup>(176)</sup> While people receiving home support services do not pay for this in its entirety, the Australian Government expects people to provide what they can towards the cost of their care and support. The remainder of the costs of the care are funded by subsidies given by the Australian Government to home support service providers for each person receiving care and support. Home support services are provided to older people, people with chronic illnesses, people recovering from surgery, and persons with disabilities.

Homecare for persons with disabilities is funded by the National Disability Insurance Scheme (NDIS), and is often called NDIS care. This includes personal care, and supports for independent living. There are two types of homecare services for older people in Australia, which are supported by government subsidies. The Aged Care

Quality and Safety Commission assesses and monitors these services to make sure they meet quality standards. These services are:

- **The Commonwealth Home Support Programme (CHSP)** which helps older Australians access entry-level support services to live independently and safely at home
- The **homecare packages programme** or simply 'homecare packages' provides support to older people with complex needs to help them stay at home.

Demand for home support services in Australia is rising. In 2014, 15% of Australians were aged 65 and over compared to 8% in 1964, and in the past 20 years there has been a nine-fold increase in the number of people aged 85 and over, up to 1.9% of the population in 2014. <sup>(267)</sup> This has resulted in an increased demand for home support services for older people, and by 2050, it is anticipated that around 80% of Australian aged care services will be delivered in the community.<sup>(267)</sup> Demand for disability services is also increasing, and the disability workforce grows by approximately 3.6% each quarter.<sup>(268)</sup>

### 3.9.2 Model of home support service delivery

This section outlines the model of home support services in Australia and how these services are delivered, supported, and governed. This section will include:

- structure and governance
- scope
- eligibility and assessment of need
- funding and commissioning
- workforce
- legislation.

### 3.9.3 Structure and governance

The Department of Health manages and develops policy for home support services in Australia. They also review the programme to ensure it continues to meet the changing needs of older Australians and carry out reforms. While aged care services are administered by the Federal Government, disability services fall under the administration of Australian States and Territories, or a mix of both Federal and States. <sup>(268)</sup>

Home support services may be provided by larger, government-run organisations, local councils, community health centers or by small private agencies. In 2012, 81% of the providers of home-based aged care packages were nonprofit

organisations.<sup>(268)</sup> Homecare packages are delivered on a Consumer Directed Care basis, which means that people have more choice regarding how their allocated homecare funds are spent, and can choose their own homecare provider.<sup>(269)</sup>

The National Disability Insurance Scheme (NDIS) is a national scheme, governed by the NDIS Act 2013, which funds homecare for people with disability for all ages. The National Disability Insurance Scheme Agency, or NDIA, is the Commonwealth agency responsible with delivering NDIS care. The NDIA administers access to care and support for people who need it, and also enables the payment for supports delivered by registered NDIS providers to participants who have their funds managed by the Agency.<sup>(270)</sup> The quality of NDIS care and supports is monitored by the NDIS Quality and Safeguards Commission against the NDIS Practice Standards.<sup>(270)</sup> Service providers under the NDIS must be registered with the NDIS Quality and Safeguards Commission, and home support service staff must comply with the NDIS code of conduct.

The Aged Care Quality and Safety Commission assesses and monitors homecare services to make sure they meet quality standards and resolves complaints made about these services.<sup>(271)</sup> Service providers must register and be approved by the commission in order to provide home support services.

The government's online platform 'My Aged Care' is the critical point for information and services. It provides:

- a central record so your information can be shared with assessors and service providers
- a consistent, streamlined assessment process
- access to relevant and accurate information
- referrals for assessments and services
- My Aged Care also sets the priority for assistance, based on your need and the availability of carers.<sup>(272)</sup>

Each person seeking home support services must register with My Aged Care and create a client record. The client record is a central up-to-date record that helps facilitate and collect information, and contains the results of care needs assessments, the level of care and support required, the value of the pension being received by the person, and what subsidies can be claimed for the person.<sup>(272)</sup> Service providers are given access to the person's client record, which minimises the person having to explain their care needs, subsidies and supplements.

People seeking home support services in Australia can receive advice and advocacy through the independent organisation 'My CarePath'.<sup>(272)</sup> This is a national aged-care support service, providing expert advice on what aged care options are available. My

CarePath can also assist people with My Aged Care paperwork, and help them to shortlist and source relevant providers.<sup>(273)</sup>

### 3.9.4 Scope

Home support services in Australia are usually called homecare, or home support, where the former is usually more complex care. The types of home support services for older persons that are available include short-term care, entry-level support at home, or more complex support at home, or a combination of these:

- **Short-term care** can be provided in both types of aged care delivered at home, and includes services that are available in the home or residential care settings for situations such as restorative care (return to independence) or to help transition a person home from hospital
- **Entry-level support at home** includes ongoing or short-term care and support services including help with housework, personal care, meals and food preparation, transport, shopping, health and social care professional services, social support and planned respite (giving your carer a break). This is provided via the Commonwealth Home Support Program (CHSP).
- **More complex support at home** includes personal care, support services and nursing, health and social care professional services, and clinical services. This is provided via the Homecare Packages Programme.

Services covered under both the Homecare Packages Programme and the CHSP, in the community and at home, include:

- social support – social activities in a community-based group setting
- transport – helps a person get out and about for shopping or appointments
- domestic assistance – such as cleaning, clothes washing and ironing
- personal care – help with bathing or showering, dressing, going to the toilet
- home maintenance – minor repairs and care of a person's house or yard, such as changing light bulbs
- home modification – install minor aids such as alarms, ramps and support rails.

Services covered specifically under the Homecare Packages Programme (and not the CHSP) include:

- nursing – a qualified nurse comes to a person's home and may, for example, dress a wound
- health and social care professionals visits – such as visits from a psychologist, physiotherapist, podiatrist, nutritionist or dietitian
- respite care – temporary care while the usual care worker takes a break

- equipment and assistive technology – emergency button and reading aids.

In November 2019, in the context of responding to the Royal Commission’s Interim Report on Aged Care Quality and Safety (final report published in March 2021), the Government announced that they were starting preparatory work to support the establishment of a single unified system for care of older people in the home. A single unified system will bring together the Commonwealth Home Support Programme (CHSP) and the Homecare Packages Programme and deliver timely and flexible care services that are tailored to consumer’s needs.<sup>(274)</sup> At the time of writing, these reforms are still ongoing.

### **3.9.4.1 Homecare Packages Programme**

To be eligible for the Homecare Packages Programme, a person needs to be at least 65 years of age or at least 50 if they identify as an indigenous person or are on a low income, homeless or at risk of homelessness.<sup>(273)</sup> This can also include older people with chronic illnesses, disability, or physical and cognitive decline.<sup>(273)</sup> The Homecare Packages Programme is also available to people with disability, under the National Disability Insurance Scheme (NDIS) Act.

Care packages are available at four levels, with level 1 being for lower care needs and level 4 being the highest care needs. The majority of the packages funded are at level 2 and level 4. The level of care that is required is determined by the Regional Assessment Service (RAS), which is a regional service that provides initial assessments of a person’s care needs, or the Aged Care Assessment Team (ACAT), which provides more comprehensive assessments if the person is determined to need it following the RAS assessment.

There are six special supplements that can be received in addition to the awarded Homecare package, and each of these have special eligibility assessments which are carried out in addition to the regional assessment service.

- Supplement 1: the Dementia and Cognition Supplement in Homecare
- Supplement 2: the Veterans’ Supplement in Homecare
- Supplement 3: oxygen Supplement
- Supplement 4: enteral Feeding Supplement
- Supplement 5: viability Supplement, and
- Supplement 6: hardship Supplement.

Under this programme, people manage their own services, and make and cancel bookings as they need them. If they are able to and wish to do so, the person receiving care and support will handle the payments directly with a service provider.<sup>(273)</sup>

### **3.9.4.2 The Commonwealth Home Support Programme**

Less complex supportive homecare is provided via the Commonwealth Home Support Programme (CHSP). To be eligible for this programme, a person must be aged 65 years or older (50 years or older for Aboriginal or Torres Strait Islander people), or be 50 years or older (45 years or older for Aboriginal and Torres Strait Islander people) and on a low income, homeless, or at risk of being homeless.<sup>(272)</sup>

As is the case with the Homecare Packages Programme, if a person is eligible for CHSP, they are expected to contribute to the cost of their care. The cost depends on the type of support and the provider. The Australian Government subsidises service providers so that fees stay reasonable and affordable. The care and support that is delivered to a person under the CHSP is based on prior assessment of their care needs by the Regional Assessment Service.<sup>(275)</sup>

### **3.9.4.3 Home support services for younger people under the National Disability Insurance Scheme (NDIS)**

The National Disability Insurance Scheme (NDIS) aims to support people to live in the community or other settings that are suitable for their age. The NDIS commenced its rollout in 2016 and gives people with significant and permanent disabilities the necessary funds to secure personal care and support, access to the community, therapy services and essential equipment.<sup>(276)</sup> The rollout of care under the NDIS scheme is administered through state and territory legislation.

If a person is under 65 years of age with a disability, they may be eligible to receive services through the NDIS. An eligible person must:

- be an Australian resident (or equivalent)
- be aged under 65 years, and
- have a disability that is permanent and significantly affects their communication, mobility, self-care or self-management.

Types of home support services that are provided to younger people with a disability include:

- personal care to help with showering or dressing, or help preparing meals and cleaning
- supports to access social, civic and community activities and keep up informal support networks with family, friends and carers
- therapy including health and social care professional supports (for example, occupational therapy, speech pathology and physiotherapy)

- specialised equipment for someone who has an ongoing problem with some activities, which are not part of the homecare package or which may be provided in the treatment of a medical condition
- modifications to make a person's home accessible.

People receiving NDIS care are asked to pay a daily basic fee, and also a means-tested contribution towards the cost of their care.<sup>(276)</sup>

#### **3.9.4.4 The NDIS Quality and Safeguards Commission**

Providers of NDIS-funded care must be registered with the NDIS Quality and Safeguards Commission (or simply the NDIS Commission).<sup>(270)</sup> The NDIS commission is an independent agency which monitors quality and safety of NDIS services, regulates NDIS providers, provides national consistency, resolves problems with services, and helps to identify areas for improvement within services. The NDIS Commission operates within each state or territory in Australia, with Western Australia being the last state to join as of December 2020.<sup>(270)</sup>

#### **3.9.4.5 National Aboriginal and Torres Strait Islander Flexible Care Program (NATSIFACP) services**

The NATSIFAC Program is part of the Australian Government's strategy to improve the quality of and access to aged care services for older Aboriginal and Torres Strait Islander people.<sup>(277)</sup> The NATSIFAC Programme funds service providers to provide flexible, culturally appropriate aged care to older Aboriginal and Torres Strait Islander people close to their home or the community. Service providers under this programme deliver a mix of residential and homecare services in accordance with the needs of the community, which are located mainly in rural and remote areas.<sup>(277)</sup>

Consumers eligible to receive services under the NATSIFAC Program are people aged 50 years and older who:

- are of Aboriginal, Torres Strait Islander descent,
- or identify as Aboriginal, Torres Strait Islander

Referrals to this programme are generally through My Aged Care, assessment teams, or regional assessment services.<sup>(277)</sup>

### **3.9.5 Eligibility and assessment of need**

The first stage in finding out if a person is eligible for subsidised aged care involves a simple eligibility check which can be done online or over the phone followed by an in-person assessment. The assessment is guided by a document known as the 'National Screening and Assessment Form'. This helps to ensure a consistent and holistic screening process that is focused on the client.

To receive a Homecare Package, each person seeking home support services must first be assessed, either by the Regional Assessment Service (RAS) only, or by the RAS and an Aged Care Assessment Team (ACAT).

My Aged Care is the entry point to the aged care system and manages a national system for prioritising access to homecare. Following the assessment, the person will be placed in the national queue, after they have been approved for a Homecare Package. Once they reach the front of the queue, My Aged Care usually refers the assessment results to a service provider who can then develop a plan in consultation with the person receiving care and support, however people can also make a referral to their preferred provider, using a referral code. The code provides a means for the service provider to access client records and help inform them of the person's needs so that a plan for delivery of care needs can be reached together.<sup>(273)</sup>

In the interim, while a person is waiting to be assigned a Homecare Package, before or after their care needs assessment, a basic package of care can be provided to address a person's urgent care needs if they require it.<sup>(272)</sup>

#### **3.9.5.1 The Regional Assessment Service**

If the person requires a Home Support Assessment, the My Aged Care Contact Centre will pass on their information to an ACT Regional Assessment Service (RAS) Home Support Assessor.<sup>(272)</sup> RAS is for older people who have low level needs, such as people seeking home support services under the CHSP who need some assistance with daily activities such as house cleaning or shopping. The RAS assessment can be done in the person's home or at another suitable place. Assessors are appropriately skilled and trained and can access client records and identify the right services for a wide range of people.

#### **3.9.5.2 Comprehensive Assessments**

If the Assessor finds that the person needs higher levels of support, they will organise a Comprehensive Assessment. A Comprehensive Assessment is conducted by an Aged Care Assessment Team (ACAT) Assessor. The information about the person seeking care and support is provided to the ACAT Assessor and they will

arrange a time to visit the person's home and find appropriate high-level aged care services.

The assessment is a comprehensive process that is focused on physical, medical, psychological, cultural, social and restorative needs. Prior to the assessment, ACATs must provide the client with the opportunity to understand the role of the Aged Care Client Record, and how their information will be shared and accessed by home support service providers.<sup>(278)</sup> The local ACAT member can be a nurse, a social worker or another healthcare professional. When carrying out the assessment, the ACAT will arrange a time to come to the person's home and talk to them about how they are managing with day-to-day life. The ACAT will also explain how the assessment works and can provide information about homecare services in the area. ACATs are employed by the State and Territory governments so each team is covered by the complaints procedures of each government.<sup>(272)</sup>

### **3.9.6 Funding and commissioning**

In Australia, home support services are either part or fully funded by subsidies paid by the Australian government directly to providers. Home support service providers can charge people a fee that they can afford to pay for their care, while the means-tested government subsidy covers the balance. Disability supports are funded by the National Disability Insurance Scheme.<sup>(279)</sup>

Each person is asked to contribute to the cost of the care and services they receive if they can afford it. People are not asked to pay the full cost of their care, as it is subsidised by the Australian Government to make it reasonable and affordable for everyone. Providers set the prices for this care and must publish these prices online on an annual basis. They must make sure the person receiving care and support has enough funding to cover their fees according to the personalised care plan.

The total amount of funding in a Homecare Package budget is made up of:

- the Government subsidy, including supplements for specific care needs if a person is eligible
- basic daily fees, payable by everyone who receives a package
- income-tested care fees, payable by people who have income over a certain amount
- amounts for additional care and services, payable if a person wants extra services that the package funding would not otherwise cover.

The Government and the care recipient pay these amounts directly to the provider.

For all CHSP services, including respite care, it is the direct client's income (rather than the carer's income) that is used to determine fees. Means testing is done by

reference to a person's pension status. Depending on their income, each person will be expected to pay:

- the standard fee, or
- the part pensioner discount fee, or
- the full pensioner discount fee.

When My Aged Care screens for eligibility, staff will ask each person to identify their pensioner status. They may ask for evidence of income status, for example by:

- Pensioner Concession Card issued by Centrelink or the Department of Veterans' Affairs or
- Commonwealth Seniors Health Card (some self-funded retirees have a low income that is recognised through the issue of a Commonwealth Seniors Health Card).

If a person is unable or not willing to provide this information they are not obligated to, however they may end up paying higher fees if a person's status cannot be confirmed.<sup>(272)</sup> Any fees paid towards CHSP services do not count towards the annual and lifetime caps on fees payable for Homecare Packages and for Residential Care.

The Australian Government reduces the subsidy for homecare providers if reductions apply. There are two types that apply to homecare – the care subsidy reduction and the compensation payment reduction, where compensation for injury or illness can be applied to the cost of their care and support.<sup>(274)</sup> The government agency involved in administering payments, subsidies and reductions to providers is called Services Australia, and providers must submit a claim form for each person every month.<sup>(280)</sup>

It has been reported that fragmented funding in Australian homecare lends itself to problems in planning, coordination, communication, and training, primarily due to the organisation of state and federal governance structures.<sup>(268)</sup>

### **3.9.7 Workforce**

The homecare worker role typically comprises personal care, domestic duties and social support, dependent upon the skills of the homecare worker, the homecare organisation, and the needs of the person receiving care and support. The majority of homecare work in Australia is performed by female, middle-aged workers, with a significant proportion from minority backgrounds.<sup>(268)</sup>

Staff working in NDIS care provision must comply with the NDIS practice standards and code of conduct.<sup>(281)</sup> There are no equivalent codes of conduct issued by the

Aged Care Quality Commission, however the workforce are expected to comply with the Aged Care Quality Standards.

A typical Australian homecare worker has attended 12 years of school and has undertaken additional study relevant to their role, such as the Certificate III in Aged Care or Home and Community Care.<sup>(268)</sup> These certificates are the most common qualifications for new entrants to the homecare sector, designed to assist homecare workers to become 'work ready' with a range of subjects focused on working safely with consumers and providing individualised care. However, formal qualifications are not mandatory for entry into the homecare workforce.<sup>(282)</sup>

### **3.9.8 Legislation**

This section outlines the legislation that forms the regulatory framework for statutory home support services in Australia.

#### **3.9.8.1 Aged Care Acts and Regulations**

The Aged Care Act 1997 (referred to as the '1997 act' in this section) is the main law that covers government-funded aged care in Australia. It sets out rules for funding, regulation, approval of providers, quality of care and the rights of people receiving care. Other Australian laws on diversity and discrimination also apply to aged care. The Australian government provides funding for homecare packages for older persons under the 1997 act, alongside the Aged Care (Transitional Provisions) Act 1997.

Multiple so-called 'principles' sit under the 1997 act which provide further detail on the provisions of the legislation. These are:

- Accountability Principles 2014
- Aged Care (Transitional Provisions) Principles 2014 – made under the Aged Care (Transitional Provisions) Act 1997
- Allocation Principles 2014
- Approval of Care Recipients Principles 2014
- Approved Provider Principles 2014
- Classification Principles 2014
- Committee Principles 2014
- Complaints Principles 2014
- Extra Service Principles 2014
- Fees and Payments Principles 2014 (No.2)
- Grant Principles 2014
- Information Principles 2014
- Quality of Care Principles 2014

- Records Principles 2014
- Sanctions Principles 2014
- Subsidy Principles 2014
- User Rights Principles 2014.

Other subsequent aged care laws apply to homecare, including the Aged Care (Living Longer Living Better) Act 2013, and the Aged Care Quality and Safety Commission Act 2018. Amendments have been made to these laws and the 1997 Act through amendment acts, including the Aged Care Amendment (Red Tape Reduction in Places Management) Act 2016 and the Aged Care Legislation Amendment (Increasing Consumer Choice) Act 2016.

The 1997 Act is subject to review on a yearly basis, and reports of this review are published online and presented to the Australian parliament. The most recent review took place in 2019-2020 and will be discussed in further detail at section 3.9.10. It should be noted that the Final Report on the Royal Commission for Aged Care Quality and Safety, published in March 2021, outlined the Australian government's intention to retire and replace the Aged Care Act as part of major reforms of the Aged Care sector.<sup>(283)</sup>

The National Aboriginal and Torres Strait Islander Flexible Care Program (NATSIFCP) is outside of the administration of the Aged Care Acts and is instead legislated for on a state or territory basis.

The Quality of Care Principles 2014 sets out what homecare providers can deliver in order to meet the quality standards. Under personal care, these approved tasks include: activities of daily living, nutrition, hydration and meal preparation, wound-dressing, and incontinence management. Under support services, approved tasks include: cleaning, personal laundry, home maintenance and modifications and other support services. Under clinical services, the legislation includes nursing and health and social care professionals, and referrals to other health and social care services.<sup>(284)</sup>

### **The Aged Care (Living Longer Living Better) Act 2013**

This Act passed the Living Longer Living Better (LLLBB) reforms into legislation on 26 June 2013, which comprised major reforms to the aged care sector. Over five years, from July 2012 to June 2017, the reforms were introduced on a phased basis to deliver more support and care at home, additional home and residential care places, a focus on greater consumer choice and control, and greater recognition of diversity and support to carers.<sup>(58)</sup> The 2013 Act created an additional 40,000 homecare places, secured additional (\$500 million dollars) funding for homecare, established the Aged Care Financing Authority and the Aged Care Quality Agency (now the

Commission), and introduced consumer directed care and means-testing for homecare recipients. Furthermore, the act created the 'My Aged Care' resource to provide centralised information about the aged care system and services through a user-centred website and a national contact centre.<sup>(58)</sup>

### **The Aged Care Quality and Safety Commission Act 2018**

This Act establishes the Aged Care Quality and Safety Commission (ACQSC), which replaced the Aged Care Quality Agency established in the 2013 act, and enables the minister to make rules prescribing matters for carrying out or giving effect to the Act.<sup>(285)</sup> These rules, the Aged Care Quality and Safety Commission Rules 2018, give operational effect to the processes of the ACQSC. These rules are regularly reviewed and amended, most recently in January 2020.<sup>(286)</sup>

The 2018 rules include provisions for monitoring of services, quality reviews of services, registration and accreditation of services and quality assessors, approvals, information governance, and complaints. The Commission Rules apply to:

- approved providers of residential aged care services, homecare services and short-term restorative care services, and
- service providers of Commonwealth-funded aged care services (this includes Commonwealth Home Support Programme and National Aboriginal and Torres Strait Islander Flexible Care Program (NATSIFACP) services).

The Aged Care Legislation Amendment (Single Quality Framework Consequential Amendments and Transitional Provisions) Act 2019 amends the Aged Care Quality and Safety Commission Rules 2018 (the Rules) as part of the transitional arrangements giving legal footing to the Aged Care Quality Standards.<sup>(285)</sup>

### **Upcoming changes to Aged Care legislation**

As part of a wide reform in the Aged Care sector, resulting from recommendations from the findings of the Royal Commission into Aged Care Quality and Safety, there are plans to replace the Aged Care Act with 'consumer focused' legislation centred on the rights of older people. This new legislation, which is still being drafted at the time of writing, is expected to come into force by June 2023 and will be underpinned by 19 human rights-based principles.<sup>(287)</sup>

#### **3.9.8.2 The National Disability Insurance Scheme (NDIS) Act 2013**

The National Disability Insurance Scheme Act 2013 (NDIS Act) established the National Disability Insurance Scheme (NDIS) and the National Disability Insurance Scheme Launch Transition Agency (known as the National Disability Insurance Agency or NDIA) and associated agencies for providing state-funded care and

supports to people with disability, including the NDIS Quality and Safeguards Commission.<sup>(279)</sup>

Among other things, the NDIS sets out:

- the objects and principles under which the NDIS will operate
- how a person can become a participant in the NDIS
- how a participant's individual, goal-based plan is prepared and reviewed, including how the NDIA approves the funding of reasonable and necessary supports
- how a provider can become a registered provider of supports
- the governance arrangements for the NDIA, including its CEO, Board, Independent Advisory Council, and Actuaries
- a process for internal and external review of certain decisions made under the NDIS Act.

As required under Section 208 of the NDIS Act, the Australian Government commissioned an independent review of the NDIS Act, which was conducted by the consultancy agency Ernst & Young (EY) between September and December 2015. This will be discussed in further detail at section 3.9.10.

### **The NDIS Rules**

The NDIS Rules are legislative instruments made under the NDIS Act. They set out the more detailed operation of the NDIS and accompany the NDIS Act.<sup>(286)</sup>

The NDIS Rules include:

- becoming a participant
- supports for participants
- children
- nominees
- plan management
- registered providers of supports
- protection and disclosure of information, and
- inter-governmental agreements.

### **3.9.9 Standards, guidance, policies and frameworks**

This section outlines the standards, guidance, policies and frameworks that are in place to support and monitor the quality of home support services in Australia.

### 3.9.9.1 Standards

In Australia there are two major sets of National Standards in place relating to home support services. These are the Aged Care Quality Standards, which apply to all aged care, and the NDIS Practice Standards, which apply to all care and support for persons with disabilities delivered and funded under the National Disability Insurance Scheme (NDIS). Prior to the development of the overarching Aged Care Quality Standards, home support service providers were expected to follow the Home Care Common Standards, which were specific to all aged care delivered in the home and were phased out in 2019.

#### The Aged Care Quality Standards (Quality Standards)

The Aged Care Quality Standards were published in 2019 by the Aged Care Quality and Safety Commission (ACQSC) and apply to all Australian Government-funded aged care services. The ACQSC monitors the quality of Australian Government-funded aged care services, and expects services to comply with these standards.<sup>(288)</sup> The standards are published alongside the 'Guidance and resources for providers to support the Aged Care Quality Standards' handbook.<sup>(288)</sup> Guidance and resources related to the standards are reviewed on a yearly basis, during which time stakeholders can provide their input on how the standards are working in practice.

Each standard contains a 'consumer outcome' which is a statement of quality expectations and rights, written from the point of view of the person receiving care and support.<sup>(288)</sup> This is followed by an 'organisation statement' which outlines what high-quality care and support provision should look like in a service, and 'requirements' which outline the responsibilities of the service provider. The eight standards are as follows:

- Standard 1. Consumer dignity and choice
- Standard 2. Ongoing assessment and planning with consumers
- Standard 3. Personal care and clinical care
- Standard 4. Services and supports for daily living
- Standard 5. An organisation's service environment
- Standard 6. Feedback and complaints
- Standard 7. Human resources
- Standard 8. Organisational governance.

Transitioning to a single set of Quality Standards for all aged care services resulted in temporary arrangements to the assessment and monitoring of aged care services which have been in place since the introduction of these standards. The ACQSC have also published guidance on these transitional arrangements to accompany the standards. These arrangements will be outlined in further detail in section 3.9.9.2.

## Home Care Common Standards

These standards were published by the ACQSC and contained specific provisions relating to the assessment of homecare service providers. As of 2019, these standards have been superseded by the overarching Aged Care Quality Standards which now cover all aged care services, including homecare.<sup>(289)</sup>

Prior to the introduction of the Aged Care Quality Standards and subsequent amendment to the regulations, the Aged Care Quality and Safety Commission Rules 2018 outlined a legislative requirement for homecare providers to adhere to the Homecare Common Standards.<sup>(286)</sup> There were three standards in total contained within the Homecare Common Standards, which were accompanied by a principle and several provider-focused statements of outcome. The standards, although no longer in use, are outlined briefly for information purposes in table 3.13.

**Table 3.13: Home Care Common Standards**

Standard	Principle	Outcomes
1. Effective management	The service provider demonstrates effective management processes based on a continuous improvement approach to service management, planning and delivery.	1.1: Corporate governance 1.2: Regulatory compliance 1.3: Information management systems 1.4: Community understanding and engagement 1.5: Continuous improvement 1.6: Risk management 1.7: Human resource management 1.8: Physical resources
2. Appropriate access and service delivery	Each service user (and prospective service user) has access to services and service users receive appropriate services that are planned, delivered and evaluated in partnership with themselves and/or their representative	2.1 Service access 2.2 Assessment 2.3 Care plan development and delivery 2.4 Service user reassessment 2.5 Service user referral
3. Service user rights and responsibilities	Each service user (or their representative) is provided with information to assist them to make service choices and has the right (and responsibility) to be consulted and respected. Service users (or	3.1 Information provision 3.2 Privacy and confidentiality 3.3 Complaints and service user feedback 3.4 Advocacy 3.5 Independence

	their representative) have access to complaints and advocacy information and processes and their privacy and confidentiality and right to independence is respected.	
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**Source:** ACQSC (2019). Home Care Common Standards.<sup>(290)</sup>

### NDIS Practice Standards

In January 2020, the NDIS published practice standards, which are aimed at providers to help them to assess their performance.<sup>(291)</sup> They provide benchmarks of what safe, high-quality supports should look like. The standards also act in tandem with the NDIS code of conduct to provide service-users with expectations of what level of quality they should expect from their care and support.

The NDIS Practice Standards consist of a core module and several supplementary modules that apply according to the types of supports and services NDIS providers deliver.<sup>(291)</sup> Each module is further subdivided into standards, which contain a set of high-level, person-centred outcomes, and quality indicators that can be used to assess the provider's level of compliance with that module. While the core module is applicable to all NDIS settings, the supplementary modules are more specific to the types of care and support being provided. For example, the supplementary module 'high intensity daily personal activities' describes specific procedures carried out during nursing care provided to NDIS participants, and what the outcomes of these procedures should be.<sup>(291)</sup>

The core module covers four components, which are further subdivided into standards:

- rights and responsibility for participants
- governance and operational management
- the provision of supports, and
- the support provision environment.

The supplementary modules apply to providers registered to provide NDIS care, and cover:

- **High intensity daily personal activities:** This module covers interventions carried out by nurses and care teams visiting people's homes, including Complex bowel care, Enteral (Naso-Gastric Tube – Jejunum or Duodenum) feeding and management, Tracheostomy management, Urinary catheter management (In-dwelling Urinary Catheter, In-out Catheter, Suprapubic

Catheter), Ventilator management, Subcutaneous injections, and complex wound management. This module highlights that these high intensity daily personal activities should be delivered in a manner that is proportionate to the needs of the person receiving care and support.

- **Specialist behaviour support:** This module applies to NDIS providers who are registered to provide specialist behaviour support to people receiving NDIS care and support. This includes behaviour support that is evidence-based and informed by best practice, least restrictive practice, and tailored behavioural support plans that are responsive, implemented effectively, and subject to monitoring and review. This module also highlights that complaints should be made if least restrictive practices are not used correctly, and that interim support plans should be made where these are necessary.
- **Implementing behaviour support plans:** The NDIS Practice Standards in this module contain more detail on the implementation of support plans, and they apply to NDIS providers who are registered to provide specialist behaviour support to NDIS participants. They also apply to providers using restrictive practices in the delivery of any NDIS supports and services.
- **Early childhood supports:** These NDIS Practice Standards apply to NDIS providers who are registered to provide early childhood supports to NDIS participants. They refer to inclusion of the child and family, collaboration, capacity building, evidence-informed practice, and highlight an outcomes-focused approach.
- **Specialised support co-ordination:** These NDIS Practice Standards apply to NDIS providers who are registered to provide specialist support co-ordination to NDIS participants.
- **Specialist disability accommodation:** These NDIS Practice Standards apply to NDIS providers who are registered to provide specialist disability accommodation to NDIS participants.

The core module is briefly outlined below in Table 3.14.

**Table 3.14: NDIS Practice Standards Core Module**

Module component	Standard
Rights and responsibility for participants	Person-centred supports Individual values and beliefs Privacy and Dignity Independence and informed choice Violence, Abuse, Neglect, Exploitation and Discrimination
Governance and operational management	Governance and Operational Management Risk Management Quality Management

	Information Management Feedback and Complaints Management Incident Management Human Resource Management Continuity of Supports
The provision of supports	Access to supports Support Planning Service Agreements with Participants Responsive Support Provision Transitions to or from the provider
The support provision environment	Safe environment Participant Money and Property Management of Medication Management of Waste

**Source:** NDIS Quality and Safeguards Commission (2020). Practice Standards.<sup>(291)</sup>

### 3.9.9.2 Guidance and implementation support tools

This section outlines the guidance and implementation support tools that are in place in Australia to support the implementation of both sets of National Standards: The Aged Care Quality Standards and the NDIS Practice Standards, for aged care and care and support for persons with disabilities respectively.

#### **Aged Care Quality Standards Transitional Arrangements Fact sheet**

This factsheet is produced by the ACQSC and provides guidance for aged care service providers on transitioning from the Homecare Common Standards and other operational standards to the overarching Aged Care Quality Standards. It describes key changes in expectations as a result of the new standards, consequential amendments to the aged care legislation, and provides deadlines and timelines for changes to accreditation and quality improvement measures.<sup>(292)</sup>

#### **Aged care quality standards guidance**

The Aged Care Quality and Safety Commission produce guidance on the Aged Care Quality Standards in order to support implementation. This guidance was updated in 2021 and outlines consumer outcomes for each standard, alongside organisational requirements for implementation of the standard. It describes the intent of the Standards and expectations of performance, along with supporting information, and examples of evidence of compliance, to inform both service-users and Aged Care Quality assessors.<sup>(289)</sup>

## **Better practice guide to complaints handling in aged care services**

In March 2021, the Aged Care Quality and Safety Commission published a guide for providers on how to handle complaints in aged care services.<sup>(293)</sup> This guide was specifically produced in order to implement Standard 6: Feedback and Complaints, which requires an organisation to have a system to resolve complaints. Compliance with this standard means that the system must be accessible, confidential, prompt and fair. It should also support all consumers to make a complaint or give feedback without fear there will be negative consequences if they raise concerns or complain.<sup>(293)</sup>

## **Effective incident management systems: Best practice guidance**

In March 2021, the Aged Care Quality and Safety Commission published a guide on incident management systems for aged care service providers as required under the Aged Care Quality Standards. This guide is intended to assist in implementing requirement 8(3)(d)(iv) of the Quality Standards, which specifically requires providers to have effective risk management systems and practices for preventing and managing incidents, including the use of an incident management system.

## **Are you alert and ready - Homecare Services**

This guide was published by the ACQSC in light of the COVID-19 pandemic. The advice is targeted to those people in the homecare service with responsibility for managing infection control, overseeing clinical care and leading business continuity planning in a homecare service. It also provides links to documents offering further advice and support.<sup>(56)</sup>

## **Aged care standards storyboards and user guides**

The Aged Care Quality Standards Storyboards are illustrated scenarios designed to provide a pictorial representation of how each of the Standards apply. They have been developed by the ACQSC for a rural and remote context to assist consumers, staff and other people interacting with aged care services to understand better, the application of the Aged Care Quality Standards in a day-to-day context.<sup>(294)</sup>

There are 11 storyboards which can be downloaded individually or as a single pack. The accompanying user guide explains the background to each story in more detail to assist facilitators who visit people and providers to help implement and explain the standards through these storyboards.<sup>(294)</sup>

## **Your Guide to the NDIS Practice Standards**

The NDIS Commission published a guide on using the NDIS Practice Standards. This guide is intended for existing providers under the NDIS, and also providers who are

seeking registration status in order to provide NDIS care. The guide is short, only three pages long, however provides a high-level overview of what steps will be expected of service providers in order to implement the standards.<sup>(291)</sup>

### **3.9.9.3 Strategies and frameworks**

This section outlines the strategies and frameworks that have been developed to support or reform the home support services sector in Australia.

#### **Homecare Packages Programme Reforms**

The 2012 introduction of the Federal Government’s “Living Longer, Living Better” programme aimed to provide greater choice and control to consumers, sets means-tested co-contributions from consumers for care, proposes increased funding for the homecare workforce, and implements stricter quality control measures.<sup>(58)</sup>

In November 2019, in the context of responding to the Royal Commission’s Interim Report, the Government announced that they were starting preparatory work to support the establishment of a single unified system for care of the elderly in the home. A single unified system will bring together the Commonwealth Home Support Programme (CHSP) and the Homecare Packages Programme and deliver timely and flexible care services that are tailored to consumer’s needs.

#### **Aged Care Diversity Framework**

The Aged Care Diversity Framework works to embed diversity in the design and delivery of aged care services. It:

- takes a comprehensive approach based on the recognition of human rights
- supports aged care service providers to improve care
- encourages consumers to be partners in the design of aged care services
- recognises that like our wider community, older people have diverse characteristics and life experiences and may need different approaches with the aged care services they receive.

The framework aims to make sure aged care services are safe and respectful of people’s diverse backgrounds and life experiences.<sup>(295)</sup>

#### **A Matter of Care: Australia’s Aged Care Workforce Strategy**

This strategy sets out 14 actions for home support service providers to change attitudes to caring, attract and retain a skilled aged care workforce, and ensure the workforce can meet aged care needs now and into the future. It was developed by the Aged Care Workforce Taskforce and released in September 2018.<sup>(296)</sup>

## **National Disability Strategy**

The National Disability Strategy (NDS) is a ten-year national plan (2010-2020) for improving the life experiences of Australians with disability, their families and carers. It seeks to foster an inclusive society that enables people with disability to fulfil their potential as equal citizens.

## **NDIS Operational Guidelines**

The NDIA produce operational guidelines in order to assist in decision-making under the National Disability Insurance Scheme (NDIS) legislative framework. The Operational Guidelines provide detail and guidance to decision makers on how to apply the law in the context of the NDIS, and helps the NDIA to interpret its functions and powers when making decisions or recommendations affecting members of the public. The Operational Guidelines also help people understand how the NDIA applies relevant laws in the daily operations of the NDIS.<sup>(297)</sup>

### **3.9.10 Findings from reviews**

This section outlines reviews of the home support services in Australia that have been carried out in recent years, including reviews of legislation which were carried out as part of the review clauses contained within Australian Aged Care and NDIS legislation. These review clauses mean that federal legislation relating to home support services (NDIS and Aged Care) must be reviewed on a regular basis, generally yearly, and reports arising from these reviews are published on government websites.

#### **3.9.10.1 NDIS Act review**

The performance of the NDIS act was evaluated in a 2019 review. This specifically recommended 'removing red tape' and making services more transparent for service-users, through reducing administrative burdens.<sup>(298)</sup>

#### **3.9.10.2 Report on the Operation of the Aged Care Act 1997 (2019-2020)**

This report details the operation of Australia's aged care system during the 2019–20 financial year. It is the 22nd report in the series. The report is delivered to Parliament by the Minister in accordance with section 63-2 of the Aged Care Act 1997. At the time of writing, the Australian Government have signalled an intention to replace the Aged Care Act 1997 as part of ongoing reforms to the sector.

### **3.9.10.3 Aged Care Quality and Safety Commission Reviews**

The Aged Care Quality and Safety Commission produce quarterly reports of homecare data in order to keep metrics and data relating to fees transparent and accessible online. These quarterly reports provide an update on the Homecare Packages Programme, and include statistics on assessment, approvals, services and people waiting for services.<sup>(299)</sup>

In 2017, the Aged Care Quality and Safety Commission held a public consultation on an integrated care at home programme, receiving over 300 responses. This consultation informed the 'Increasing Choice in Home Care' reforms. These reforms took effect in 2017 and included packages assigned to individuals instead of providers, one national priority system, and less paperwork for providers.<sup>(267)</sup>

Similarly in 2017, a public consultation on the Single Framework for Aged Care Services was held. In total, around 350 submissions were made. Over 250 consumers, carers, providers, peak organisations and other sector representatives also attended video conferences or forums held across Australia.<sup>(269)</sup> Subsequent to the public consultation on the Single Quality Framework an independent review of Commonwealth aged care regulatory processes was launched. The findings from this review prompted a recommendation of further reforms in March 2021.<sup>(283)</sup>

### **3.9.10.4 Respect, Care and Dignity – The Final Report from the Royal Commission into Aged Care Quality and Safety**

The Final Report from the Royal Commission into Aged Care Quality and Safety was published in March 2021 and tabled in Parliament, containing significant proposals for reform of the aged care sector.<sup>(283)</sup> The report contained 148 recommendations on the future of aged care in Australia, most notably the recommendations to replace the Aged Care Act 1997, and the establishment of a new commission, the Australian Aged Care Commission, to replace the Aged Care Quality and Safety Commission. Many of the other recommendations directly related to reform of home support services, for example minimum qualification requirements for personal care workers, merging the homecare packages and the Commonwealth homecare programme, thereafter referring to homecare as 'care at home,' standardisation of processes and documentation relating to payments, clearing of waiting lists, and increased funding for respite services and provider training and education.<sup>(287)</sup>

### **3.9.10.5 Respect, care, dignity: A generational plan for aged care in Australia**

In May 2021, a strategy for aged care informed by the findings from the Respect, Care and Dignity report was published. This plan outlines how a \$17.7 billion aged

care reform package, which has been allocated in response to the findings from the Royal Commission into Aged Care Quality and Safety, will be used to deliver a 'once in a generation' reform of aged care by the year 2025. This plan is based on four pillars:

- Homecare - supporting senior Australians who choose to remain in their home
- Residential aged care services and sustainability - improving and simplifying residential aged care services and access
- Residential aged care quality and safety - improving residential aged care quality and safety
- Workforce - supporting a growing and better-skilled care workforce
- Governance - new legislation and stronger governance.

According to this plan, an additional 40,000 homecare packages would be released in 2021-22, rising to 275,000 by 2023. The Government will also design and plan a new support at home programme to replace the Commonwealth Home Support Programme, Homecare Packages, Short-Term Restorative Care and residential respite programmes, which will commence from July 2023. The Government will extend the Commonwealth Home Support Programme for one year to 30 June 2023 while preparing for and designing the new programme (\$10.8 million), which will be developed in consultation with older people and community stakeholders. Furthermore, \$798.3 million has been allocated to supporting informal and family carers, particularly those caring for family and loved ones with dementia, with a focus on improving access to respite services and support programmes.

The plan also outlines planned improvements to the quality of care in dementia, diversity, food and nutrition services, and a Community Care Finder service of up to 500 staff will be rolled-out in order to help people to find and access specialised support if they need this. Older people receiving in-home and residential aged care will be supported by 6,000 new personal care workers, with additional surge workforce capacity in regional and remote locations, and additional nurses recruited via targeted incentive schemes. Furthermore, over 30,000 additional training places will be made available for personal care workers wishing to receive a Certificate in Individual Support (Ageing). Overall, the plan aims that by 2025, people will receive sustained, high quality aged care, with support matched to assessed individual needs.

### **3.9.11 Summary and lessons for Ireland**

Homecare is regulated in legislation in Australia through the Aged Care Act 1997 and the National Disability Insurance Scheme Act 2013. These regulations provide legal footing for home support services, however do not specifically outline the scope of tasks involved in these services. This may provide flexibility in terms of what types of

care can be provided in the home, allowing the care worker to adapt care delivery as a person's needs arise during visits. This may change however with the introduction of new legislation, as recommended by the report on the Royal Commission for Aged Care Safety and Quality.

In Australia, legislation and guidance undergoes regular review, as required by review clauses within Australian legislation. This allows problems or restrictions with the legislation to be identified early, and on an ongoing basis. Although standards themselves aren't subject to mandatory review, having such a system in place in Ireland could improve knowledge of how regulations are working 'on the ground' and potentially reduce reliance on complaints from care workers or service providers for identifying problems.

The NDIS Professional Standards are linked with a code of conduct, which outlines how the standards should be applied in practice from the point of view of the care worker, and provides an accessible way of translating the standards to the workforce. This means that care workers do not have to remember the standards themselves, but instead they are integrated into the conduct that is expected of them. Likewise, while the Aged Care Standards are from the point of view of the person receiving care and support, they contain 'requirements' for how standards should be applied in daily practice. Having such a practice in place helps care workers to apply standards in their daily work.

In Australia, access to both Aged Care and NDIS care is means tested, but people will only be expected to pay what they can afford to. In the case of aged care, this is carefully regulated by standardised pricing and transparency in terms of what these prices mean, and registration of the people receiving care and support on a central database 'My Aged Care'. Access to home support services for aged care is linked with pensioner status, and this provides a simple way of 'proving' financial status while being assessed for care needs. Having such a process in place may provide clarity on what kind of fees a person would be expected to pay, and may streamline processes for organising homecare.

### 3.10 Other international examples

There have been a number of recent international evidence reviews which have examined and compared how homecare and support is delivered in a number of countries globally. This international evidence shows that there is a strong focus on the importance of homecare and support in many countries to prevent unnecessary acute and long-term institutionalisation and to maintain people in their homes and communities as long as possible.<sup>(300)</sup> The EIT Health, which is a body supported by the European Institute for Innovation and Technology, an agency of the European Union, highlighted the importance of supporting people to age in place with the enhancement of homecare services. Service providers and homecare workers should be trained to deliver care and support on a needs-led basis and to be able to supplement care and support of older persons with digital health and assistive technologies.<sup>(18)</sup> The Danish National Action Plan on Dementia 2025, published in 2017, recommends building housing communities for people with dementia so that they can live in a home environment for as long as possible.<sup>(301)</sup>

A systematic review of the literature found that there is a large variation in the homecare regulation, governance, financing and delivery and availability of services among 18 European countries.<sup>(209)</sup> The WHO highlights the importance of integration and coordination between homecare providers and the health and social care sector.<sup>(18)</sup> Some European countries such as Portugal and the Netherlands reported challenges in the integration of homecare, including poor service coordination due to the high number of care professionals involved in one person's care and different budgets for health and social care at home. Such challenges could be overcome by having different professional disciplines working in a home support provider or agency and case managers. Case managers were already in place to coordinate homecare services in five countries (England, Iceland, Sweden, Italy and Finland). Other countries such as Denmark and Sweden reported having integrated care teams with home support organisations providing multiple aspects of homecare.<sup>(209)</sup> Indeed, the Organisation for Economic Co-operation and Development (OECD) also reported the need for collaboration between homecare services, informal carers, and long-term care providers as the demand for older person's services grows with increasing longevity.<sup>(14)</sup>

The evidence also shows poor working terms and conditions for homecare workers across European countries. This includes irregular working hours, lack of management support and workload pressures, resulting in staff burnout.<sup>(209)</sup> The International Labour Organisation published a report in 2018 that outlines the burden of care on women and family carers. It examines how an ageing population will lead to increased constraints on the sector as demand outpaces supply. While this report is not specific to homecare, the outcomes are applicable. For example,

the report mentions the 'personal care worker' which is usually home-based and examines the low wages and poor working conditions of this role.<sup>(302)</sup>

### 3.11 Summary of international review

The international review set out in this document provides an overview of how Scotland, England, Northern Ireland, Wales, the Netherlands, Australia and New Zealand deliver homecare and support services to people in their jurisdictions. The evidence shows that each jurisdiction has legislation, strategy, policy, and service delivery systems in place for homecare and support services.

The core messages from the international review can be summarised as follows:

#### **Legislation and policy**

- There is a need for a standardised definition of what is meant by homecare and home support and what it constitutes to ensure clarity of scope, so that it can be adopted consistently across all Irish health and social care services.
- Standards should be aligned with legislation and regulations, but standards can also offer 'stretch goals' for quality improvement over-and-above the regulations.
- Clear governance structures are required to ensure corporate and clinical oversight and accountability.

#### **Standards and regulations for homecare and support services**

- The scope of the standards should be clear and all relevant services should be included within the scope.
- The standards and the system of regulation need to be attainable, in order not to exclude smaller providers.

#### **Outcomes**

- Homecare standards should be outcome based, person centred and make sense to both provider organisations and individual service users.
- In addition to being outcomes focused and person centred, standards should be holistic in approach and consider the social and emotional wellbeing as well as the physical wellbeing of the service user.

#### **Eligibility**

- The service provided should be based on assessed needs, rather than the person's diagnosed condition(s).
- A focus on equity and accessibility (for example, minority groups) within the standards is recommended.

- Eligibility criteria for services should be clear and transparent, with a standardised, transparent assessment process, which is easy to navigate.
- All the jurisdictions reviewed noted that homecare and support services have fragmented into three key areas of delivery: older people; adults with disability; and children.

### **Partnership**

- Service users, their families and providers are equal and key partners in the development and implementation phases of standards and should also be included in assessment of organisational performance against those standards.

### **Facilitation of implementation**

- There is a need to incorporate lead-in time for implementation of standards.
- Provider organisations require significant levels of support to implement standards and provide appropriate evidence of attainment of those standards.

### **Workforce**

- The workforce is central to the delivery of high quality, person-centred homecare and support services. Any standards for this service must include consideration of the need to grow and develop this workforce.
- A number of countries have introduced registration of care workers, training and pathways for career progression, facilitating professionalisation and delivery of increasingly complex care.

All of the countries reviewed are exploring how to move from a regulatory environment that focuses primarily on organisational processes to one that focuses instead on user-led outcomes, placing the service user at the centre of all aspects of homecare services. The evidence shows that each jurisdiction has legislation, strategy, policy, and service delivery systems in place for homecare and support services. The main findings and learning from the international jurisdictions are as follows.

#### **3.11.1 Legislation and policy for home support services and increasing complexity and need**

In all of the countries included, there was clear government policy, through strategy and framework documents, to support people to remain cared for in their own homes for as long as possible. Like Ireland, there was also a reliance on informal carers in all countries studied. The majority of this legislation includes, either in primary legislation or associated statutory guidance, clearly-defined boundaries for

homecare and support or provides examples of what tasks are included in these services. A key message from other jurisdictions is to streamline the legislative context for homecare wherever possible and to ensure that the rationale for any standards are made explicit, in order to assist providers to demonstrate compliance with legislation and associated regulations.

Home support services were referred to by a variety of terms in the seven countries included in this review. For example, the following terms were used: home support, care at home, domiciliary care, homecare and home help. Even within some countries, more than one term is used. This lack of a standardised definition and interpretation can lead to challenges in what is meant by home support services at a local delivery level, for example between trusts or local authorities. Therefore there is a need to develop a standardised definition and ensure clarity of scope of what is meant by homecare and home support and what it constitutes, so that it can be adopted consistently across all Irish health and social care services.

### **3.11.2 Standards and regulations for home support services**

Northern Ireland was the only country out of the seven countries studied that had a dedicated mandatory set of standards specifically for homecare. These standards form an integral part of activities to regulate, inspect and monitor domiciliary care services. The National Institute for Health and Care Excellence (NICE) *Home care for older people* quality standard applies to England and Wales, but these standards are not mandatory or enforceable. The remaining countries had overarching standards that apply either to all health and social care services (Scotland and New Zealand) or all older person's services (Aged care Australia) or all disability services (National Disability Insurance Scheme Australia).

All countries reviewed, with the exception of New Zealand, have regulations related to homecare in place. All countries include personal care (activities of daily living) within these regulations. Personal support activities or instrumental activities of daily living (IADL) are included under regulations in Scotland, Australia and the Netherlands. In England and Wales, services that provide personal support activities (IADL) only are not regulated. However, if a service is regulated to provide personal care, personal support services will be reviewed during inspection. At interview with the Care Quality Commission in England and the Care Inspectorate in Wales, both recommended that both personal care and personal support should be included within regulations, in order to ensure services are more person centred and focused on the needs of the person and to eliminate any grey areas in regulation.

Interviewees also recommended that nursing care should be included in the scope of standards and regulations for homecare, especially as homecare becomes increasingly complex, and that it may be restrictive to exclude this aspect of care

and support. In addition, interviewees recommended that while standards should align with regulations, they should also offer 'stretch goals' for quality improvement over-and-above the regulations.

### **3.11.3 Age related services and eligibility**

While homecare and support is generally associated primarily with services designed to support older people, in all seven jurisdictions reviewed, homecare and support services also provided support to adults aged 18 to 65 years and to children and young adults. There is, however, significant variation within each jurisdiction reviewed in respect of how services to support children are regulated and quality assured.

All the jurisdictions reviewed noted that homecare and support services have fragmented into three key areas of delivery: older people; adults with disability; and children. This fragmentation is reflected in complex regulatory and monitoring arrangements.

It must be noted that increased specialisation of this nature is often considered a powerful driver for improvement in the quality of care delivered. However, for service users, this categorisation is often perceived as an organisational or administrative convenience that does not always make sense to the person using the service and their family. Additionally, significant resources are required to assist service users to transition from one service area to another, such as children moving from Children's Services to Adult Services and to manage risks associated with moving out of one support system and into another.

It may be important to consider whether having very defined age limits or brackets for homecare and support services could actually present barriers to access, or contribute to increased risk of service failure at points of transition from one category to another.

### **3.11.4 A focus on service user outcomes in monitoring home support services**

A number of countries included in this review had a strong focus on service-user outcomes in their monitoring and regulation of homecare and support services. A good example of this can be seen in Wales, where in the past, regulations, standards and inspection methodologies brought in under the Care Standards Act 2000 were criticised for a focus on the various operational and governance processes characteristic of a well-run organisation, rather than user-based outcome measures. Domiciliary care is now regulated by the Care Inspectorate Wales against a regulatory framework put in place under the Regulation and Inspection of Social

Care (Wales) Act 2016. This has changed the way that services are registered and inspected, with a focus on wellbeing outcomes for people using services and improving quality of care and support. This transition provides valuable learning to Ireland in terms of its development of regulations and associated standards for homecare and support services, which focus on the outcomes important to people using the service.

Additionally, in Scotland, the Quality Frameworks against which the Care Inspectorate monitors and inspects home support services adopts an outcomes-focused approach, where a holistic view of the person receiving care and support is emphasised.

In Wales, New Zealand, Australia, the Netherlands and England, approaches to person-centred, outcome-focused assessment of need, care planning and evaluation are enshrined in legislation, for example the Care Act 2014 (England); Social Services and Wellbeing (Wales) Act 2014; and the Health and Disability Services (Safety) Act in 2001 in New Zealand.

Other jurisdictions include a strong focus on individual as well as clinical outcomes for users, for example the Dutch Institute for Accreditation. In Australia, the Home Care Common Standards (2018) have been effective in driving change towards an outcomes-based system of accountability.

Having such a focus may ensure that inspections of homecare and support services are not restricted to a compliance versus non-compliance approach, which may result in some aspects of care and support delivery, such as the person's wellbeing and quality of life, being overlooked as indicators of how well the service is performing. Furthermore, an outcomes-focused approach may highlight the importance of the person's voice in the inspection process and establishing what outcomes are most important to them. As a result, it would be useful for the development of inspection frameworks to involve consultation with people experienced in delivering and receiving care at home.

A focus on outcomes reflects a more general move towards citizen participation, empowerment and personalisation of service design and delivery, and therefore of new standards for the service. It also provides opportunities to involve the service user and or their families in the assessment of the quality of the service they are receiving. A number of countries such as the Netherlands, Australia and New Zealand already include the service user and or their families in the monitoring and evaluation process, with other jurisdictions for example, Scotland and Northern Ireland actively seeking ways to do so.

Models are emerging of how this shift can be achieved, including in Wales, New Zealand, Australia and the Netherlands. However, it should be noted that each of these jurisdictions also noted the considerable challenges in translating broad principles of independence, participation and customisation into practice.

### **3.11.5 Eligibility for home support services and assessment of need**

In all of the countries studied, eligibility for home support services was primarily based on the care and support needs of the person. All countries, except the Netherlands, include an assessment of the person's finances when determining their eligibility for free or part-subsidised care and support.

It is important that all potential recipients of homecare can be assessed using the same criteria. The adoption and full implementation of a standardised tool for assessment offers a consistent and comprehensive approach to assessment and thus will reduce the likelihood of variation and risks in care delivery. Assessments of care needs should place the care recipient at the centre of the process and should also incorporate the views of their family or representatives, as well as their community and primary caregivers. These assessments should be subject to regular review, to identify and respond to people's changing care needs as they emerge.

### **3.11.6 Funding**

All jurisdictions reviewed reported that funding structures to deliver homecare and support services appear complex and piecemeal. Elements making up the funding streams range from central government allocations, general taxation, mandatory social insurance (for example, in the Netherlands), local government funding and personal contributions. This complex web of funding can be confusing, not only for prospective service users, but also for provider organisations who must meet contractual reporting and monitoring requirements for a range of funders, in relation to activity and various quality indicators.

A single standard or suite of standards for care and support at home has the potential significant benefit of delivering a single, coherent, comprehensive governance structure, agreed management data returns and quality measures that meet the requirements of all funders, in addition to the needs of the population.

### **3.11.7 Partnership Working**

All countries interviewed noted that not only are they moving to a more outcomes-based, personalised approach to the development and application of standards, they are also considering how provider organisations are included in the process of developing and monitoring the standards themselves. Mechanisms for this vary, with the Home and Community Health Association in New Zealand, which engages with

the New Zealand government to establish, promote and recognise high standards of practice, perhaps the most well established.

Across jurisdictions, interviewees also commented on the importance of co-working with provider organisations through the standards development process and in the provision of tools to support providers to implement the final standards in their own organisations.

### **3.11.8 Integration, Accessibility and Proportionality**

Interviewees noted that as services move to a more outcomes and person-centred model of delivery, there are significant opportunities through the design and development of standards to promote closer integration between different aspects of support to people in their own homes: for example, general practitioner (GP) services; acute care; and community care.

All interviewees reported working in complex systems, with every jurisdiction reporting significant variation, not only in the characteristics of those using the service, but also in the composition of provider organisations seeking to deliver high-quality care and support. These organisations can range from one or two people coming together to support an individual, to large multinational companies. Interviewees noted that the standards must be easy to apply to organisations of any size or complexity.

Interviewees also emphasised the importance, not only of clarity and consistency in the application of standards, but of adopting a proportionate approach to the level and nature of management data and user feedback required to demonstrate compliance with the standard. Similarly, if standards are to provide assurance and inspire confidence in users and their families, they should be designed and written in ways that make sense to individuals and families, not just providers, commissioning bodies and or regulators.

Alongside that, many interviewees noted the importance of reducing unnecessary demands on providers, while maintaining high levels of compliance and quality assurance, as a challenging but necessary task.

### **3.11.9 Communication**

Interviewees noted that homecare and support providers are uniquely placed to identify potential deterioration or changes in respect of a person's health and wellbeing at an early stage. Appropriate communication with the user and or their family, the GP or lead health and social care professional and the commissioning organisation is central in promoting and maintaining levels of wellbeing, and standards should reflect the importance of timely communication.

There was some variation across the countries interviewed in how and when core information about the service-user, their needs, aspirations, preferences and desired outcomes are communicated with provider organisations: for example, in the UK providers are given a list of tasks to be carried out, whereas in the Netherlands providers have access to a full comprehensive assessment, enabling full participation by the user in the design of the plan for delivery of their care and support.

Communication is therefore recognised by all countries interviewed as a key element of any standard, whether with the user, provider, healthcare professional or commissioner of the care.

### **3.11.10 Barriers to implementation**

All seven respondents noted that there are some key challenges that arise in the introduction of standards for homecare and support services.

All interviewees noted that the 'market' of homecare and support providers is perceived as fragile, with different levels of provider-maturity posing risks that any additional reporting requirements may either be unachievable or too onerous for providers to complete. There was a sense that, if regulation and standards are fragmented across user-categories, then some providers may choose to restrict their activity to the sector that is not yet regulated, or where it is perceived that the standards are 'easier' to attain, thereby creating a risk of unintended consequences.

As noted elsewhere, homecare and support services are delivered in a complex network of funding and commissioning arrangements. It is important that there is consistency of approach by all parties involved so that providers have, wherever possible, a single set of quality standards and monitoring returns.

Finally, interviewees all reported that implementation of new or revised standards is resource intensive for regulators and providers alike and that realistic levels of

Factors that facilitate implementation

Interviewees advised that there were a number of factors that can assist and expedite successful implementation of standards. System leadership by the regulator or inspecting authority was seen as perhaps the most important factor. This can manifest in many different ways, including: consistency of approach; clarity of expectations; design and delivery of implementation support tools and worked examples; and flexibility in assessing and validating evidence of compliance.

All interviewees noted the importance of working with providers and users to both co-produce the standards and to develop innovative ways of assessing evidence. For example, the Netherlands regularly audits user experiences and also requires providers to submit core performance and activity data on an annual basis.

Colleagues in Australia strongly advocated a phased approach to introduction of standards, and are moving forward on a state-by-state or geographical basis. While acknowledging that this could mean a significant delay for some providers and service users, their experience suggested that implementation is very resource intensive and a modular approach was ultimately more effective.

### **3.11.11 Workforce**

Respondents were unanimous in noting that homecare is a human service, delivered to people by people. The imperative of moving away from a process-focused to person-focused approach to standards is recognised as placing increasing emphasis on ensuring that the workforce is properly equipped to deliver high-quality care and support services to people in their own homes.

Every jurisdiction noted similar challenges in relation to recruitment, retention and remuneration of the workforce. All noted the importance of developing not only the status of homecare and support work, but of upskilling the workforce to deliver increasingly complex care at home, with Northern Ireland perhaps the most advanced jurisdiction in respect of both regulation and mandatory training arrangements.

In four of the countries studied (Scotland, Wales, Northern Ireland and the Netherlands), it is compulsory for home support workers to register with a professional body.

In England there are currently no formal requirements for registration of staff working in home support services but there are minimum qualification requirements for general domiciliary care staff. Similarly, home support workers are unregulated in New Zealand but are accountable under the Health and Disability Commissioner Act 1994 and must adhere to the Code of Health and Disability Services Consumers' Rights. In addition, the New Zealand government has enacted legislation to address challenges and has placed duties on the sector to value workers as a central part of the health system.

A lesson that can be drawn from these countries is the emphasis that is placed on the role of the social care workforce, recognising their contribution to society, and seeking to improve retention through improved working conditions and wages. The need to develop the social care workforce, providing ongoing education and training was also supported internationally.

## **Evidence synthesis**



## 4. Evidence Synthesis Methodology

### 4.1 Overview of the evidence synthesis process

HIQA undertakes detailed syntheses and reviews of existing evidence to inform the development of national standards. These reviews describe the Irish and international context in which the work is being conducted and ensures that the work is informed by quality evidence and reflects international best practice. This is detailed in HIQA's *Evidence Synthesis Process: Methods in the development of National Standards, Guidance and Recommendations for the Irish health and social care sector*.<sup>(303)</sup> The evidence synthesis process has two phases: Phase 1 involves a scoping review and Phase 2 consists of a systematic search and literature review.

### 4.2 Scoping review

The scoping review was a time-limited review and was a preliminary assessment of the potential size and scope of the existing literature and how long it would take to review relevant literature. Through the scoping review, relevant databases and websites were identified. Three grey literature repositories were identified: Lenus, Open Grey and HEN. The academic databases identified were: Embase, APA PsychInfo, Social Services Abstracts, and CINAHL. The scoping review also informed the development of a tailored research question, search terms and search limiters. The returns were catalogued according to the type of article and the source of the article. The findings from the scoping review were integrated and used to inform Phase 2 of the evidence synthesis.

### 4.3 Objectives

The aim of the evidence synthesis was to assess and appraise available evidence to identify characteristics of good person-centred practices in home support services, where people experience safe, high-quality outcomes from the care and support they receive in their home.

Phase 2 of the evidence synthesis included the following objectives:

- To conduct a formal systematic search of the following literature sources, as identified in Phase 1:
  - grey literature repositories
  - academic databases
- To screen all articles for inclusion in the evidence synthesis
- To conduct a quality appraisal of all included articles in the evidence synthesis
- To describe and critically evaluate the articles and to identify emerging themes
- Search strategy methodology.

### **4.3.1 Conducting a formal systematic search**

Search terms identified in Phase 1 of the evidence synthesis were used to identify, retrieve and evaluate literature from academic databases and grey literature repositories between 2010 and 2022. Five electronic academic databases were searched between February and May 2021: Embase, APA PsychInfo, Social Services Abstracts, and CINAHL. A combination of search terms was used; these related to the setting (for example 'healthcare', 'social care' and 'mental health') and the topics of interest (for example, 'person-centred', 'high quality', 'safe' and 'effective'). Terms such as 'practice', 'standard', 'guidance', 'guideline' and 'recommendation' were included to ensure that the search focused on standards in health and social care. The full list of terms used to search the academic databases is shown in Table 4.1.

#### **Table 4.1: Search terms used to search academic databases**

<b>Concept 1</b>	<b>Concept 2</b>	<b>Concept 3</b>	<b>Concept 4</b>
Adult	Homecare	Personal	Standard
Child*	Homecare	Nurs*	Guid*
Adolescen*	Domicil*	Household	Practice
Teen*	In-home	Domestic	Principle
Youth	Home support	Community	Framework
Young*	Home help	Primary care	Tool
Aged	Care at home	Healthcare	Person-cent*
Older	Support at home	Health care	Quality
Elderly	Care and support at home	Social care	Safe
Paediatric	Treatment at home	Mental health	Evidence-based
Pediatric		Disabilit*	Outcomes
Client		Reablement	Experience
Service-user		Companionship	
Patient			
Recipient			
Geriatric			
Participant			

The three grey literature repositories (Lenus, Open Grey and HEN) were also searched. The search terms used for the academic databases were also applied to the grey literature, however it was not possible to apply all combinations of search terms at one time. A more sequential approach was taken, with each source being searched iteratively using the agreed search terms outlined in Table 4.1.

#### **4.3.2 Screening articles for inclusion**

Evidence was deemed to be eligible for inclusion in the evidence synthesis if it described elements of principles that underpin the development of standards in

health and social care services. Quantitative, qualitative, mixed methodologies and reviews were considered in the evidence synthesis. The following exclusion criteria were applied at three stages of study selection (screening by title, screening by title and abstract and during the assessment of the full text):

- documents focusing on settings outside of scope (non-health or social care settings)
- documents focusing on developing countries
- books, book reviews, editorials and letters.

#### **4.4 Scoping consultation and suggested resources**

The scoping consultation invited respondents to suggest evidence and resources for inclusion in the evidence-base to inform the standards. Altogether, 158 publications were sourced via scoping consultation responses, and these included academic literature, white papers, government documents, implementation support materials, frameworks, policies and strategies. These were reviewed and appraised, and relevant data were extracted and incorporated into the document where appropriate.

#### **4.5 Summary of search results**

Figure 4.1 depicts a flow chart of the selection process for relevant articles, based on the combined evidence. Following the removal of duplicates, 17,341 documents were identified for inclusion. Two researchers conducted initial title and abstract screening for potential inclusion. An independent reviewer reviewed all of the identified titles and abstracts again for potential relevancy. The remaining documents were read by two authors to determine eligibility for inclusion. Discrepancies about whether a paper or document met the inclusion criteria were discussed with a third reviewer and a final decision was made based on consensus. 248 documents were identified for inclusion in the evidence synthesis following a review of full texts.

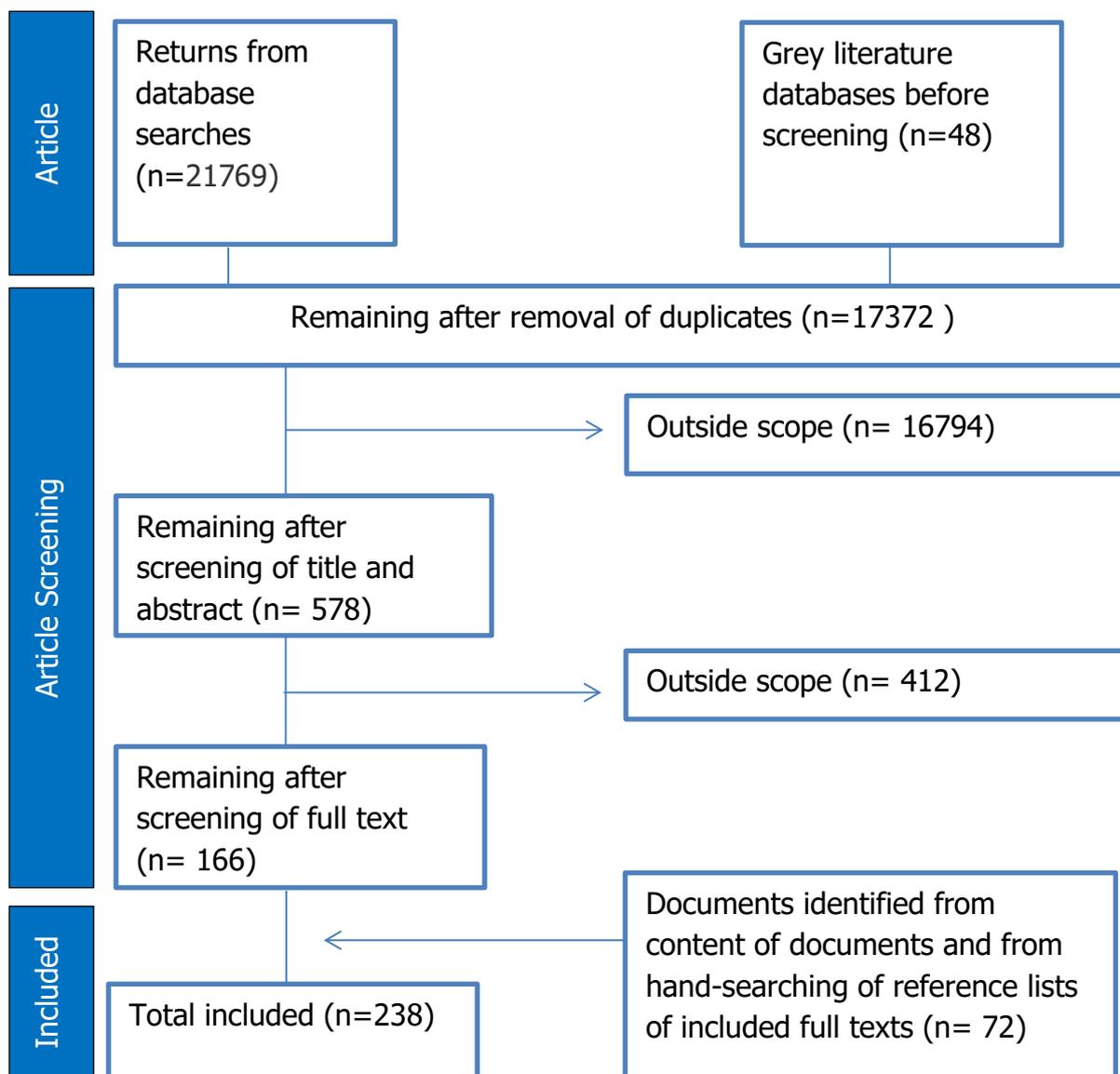
##### **4.5.1 Quality appraisal**

The AACODS checklists were used to appraise the quality of the grey literature and assessed the literature using the following criteria: Authority, Accuracy, Coverage, Objectivity, Date and Significance. Grey literature articles assessed through this process made a significant contribution to the evidence synthesis. The articles came from reputable and credible authors or organisations and the findings were presented in a balanced and objective manner.

The Mixed Methods Appraisal Tool (MMAT) was used to assess the quality of empirical studies. The Critical Appraisal Skills Programme (CASP) was used to evaluate systematic reviews. Peer-reviewed academic articles were also assessed

using the AACODS checklist as they did not have a methodology consistent with a particular MMAT or CASP checklist.

**Figure 4.1: Prisma flow chart of evidence synthesis**



## 5. Evidence Synthesis Findings

### 5.1 Structure of the literature review

Synthesised findings from the review of academic and grey literature relating to homecare and support services are outlined in this section. The evidence synthesis is

structured under the following four principles, as per the HIQA Standards Development Framework<sup>(2)</sup>:

- Human rights-based approach
- Safety and wellbeing
- Responsiveness, and
- Accountability.

## 5.2 Human rights-based approach

The principle of a human rights-based approach (HRBA) means that health and social care services respect, protect and promote the human rights of the person receiving care and support at all times.<sup>(304)</sup> The HIQA Standards Development Framework describes how a person should experience a human-rights based approach as follows:

*My rights are protected and promoted by health and social care services and are explained to me in a way that I can understand. I am treated with dignity and respect and I do not experience discrimination for any reason when I am accessing or using services. I am valued and recognised as an individual who is able to participate in and exercise control over my life. I have a right to participate in decisions about my care and support, and when appropriate my family and the people caring for me are included in this process. Services work to support my participation. This ensures that I, and the important people in my life, can express our views, feelings and wishes in order to effect change in the care and support that I receive. <sup>(2)</sup>*

### 5.2.1 Introduction

It is widely recognised that applying a human rights-based approach to care and support promotes a person-centred, safe and quality service. A human rights-based approach places the person and their human rights at the centre of all that a service does. Human rights are rights that all people should enjoy and are protected by a legal framework and human rights treaties, which Ireland has agreed to uphold, for example, the European Convention on Human Rights Act 2003, the United Nations Convention on the Rights of Disabled People 2006 and the Charter of Fundamental Rights of the European Union 2000.

Human rights are about people being treated with fairness, respect, equality and dignity, having a say over their lives and participating as fully as possible in decisions about their care and support. In 2019, HIQA and the Mental Health Commission published guidance on how to uphold a human rights-based approach to care and support for adults in health and social care services. This guidance is set out under

the FREDA principles, through which human rights can be considered. The FREDA principles can be used as a lens through which home support providers can apply a human rights-based approach in caring for people living at home and thus safeguarding them, especially vulnerable populations. The five principles making up the FREDA framework are Fairness, Respect, Equality, Dignity and Autonomy.<sup>(43)</sup>

This section will summarise findings from a review of the literature under components that make up a human rights-based approach, in the context of supporting homecare and support services to protect a person's right to dignity and respect, autonomy, participation in one's own care and support, equality and communication. These components are interdependent, and in some instances overlap.

The review of the literature on homecare and support found a number of studies relating to rights-based care. Across 17 relevant studies, there were a total of 120,704 participants and 11 service providers across 12 primary qualitative studies, two primary quantitative studies and one mixed-method study. The age of participants ranged from 18 to 95 years. In addition, one scoping review and one integrative literature review were included. The studies reviewed reflect the perceptions and experiences of what living at home means to a person receiving homecare and what their care and support needs are. Common themes that emerged from the studies are described under the following subheadings:

- Dignity and Respect
- Autonomy
- Participation
- Equality
- Communication.

### **5.2.2 Dignity and Respect**

Dignity and respect are central to providing person-centred care that recognises the meaning of homecare and support to a person. The concept of 'personhood' was discussed in three studies<sup>(305-307)</sup> and captures the essence of person-centred care. Personhood is referred to as a 'sense of self'<sup>(306)</sup> and describes a focus on the whole person being actively involved in their own home and life, to subsequently bring meaning to one's life.<sup>(305)</sup> According to a 2018 study,<sup>(307)</sup> personhood requires the person to be seen as a partner in their own care and thus, homecare and support services should seek to determine the extent to which a person wishes to be involved as a partner in their own care.<sup>(307)</sup> In doing so, homecare and support providers need to accept and acknowledge the values and preferences of a person.

However, this may prove challenging for homecare and support providers to see the 'sense of self' or personhood at all levels of a person's functional and cognitive ability.<sup>(307)</sup> A change in a person's circumstances, for example a decline in functional or cognitive ability, may result in a home support worker feeling challenged to fully involve the person in their own care and support due to time constraints. Subsequently, this may lead to a loss or violation of the person's dignity.<sup>(307)</sup>

Respect for a person is influenced by values and beliefs in human dignity.<sup>(307)</sup> There is a strong connection between who the person is, that being their identity, their dignity and their home. The home is where the person lives and carries out their habits and routines every day, all of which evolve to distinguish a personal identity.<sup>(306)</sup> As such, homecare and support providers need to take into account that a home represents a sense of identity for the person and a sense of inclusiveness which gives meaning to one's life.<sup>(308)</sup> In order to maintain a person's identity, services need to be tailored to the individual's needs, so to redefine normal day-to-day living for that individual.<sup>(309, 310)</sup> In addition, the introduction of formal carers and medical equipment has the potential to interfere with personal space and subsequently place the home at risk of becoming a work or clinical environment. Moreover, a person's home is a private space that can become impacted by rules and regulations when formal carers enter.<sup>(306)</sup>

Participants who took part in a study in England to explore older people's experiences of formal homecare, with an emphasis on autonomy and respect, reported that introducing care equipment into a home brings about a sense of a 'mini-institution' and carers then tend to focus on the task at hand as opposed to the person.<sup>(306)</sup> This study also highlighted that care can be enhanced through understanding the sense of self and the value that the person places on their home space. The likes and dislikes of the person are unique to that person and their circumstances and hence, a generic approach to homecare and support is not a person-centred care approach.<sup>(306)</sup> In essence, the conduct of the homecare and support provider has a direct impact on the person feeling respected as a person.

Older people who participated in a study conducted in Australia highlighted the need for providers to support the viewpoint that older people 'know best' and should facilitate efforts to support this view.<sup>(307)</sup> Similarly, a study conducted in England reported that older participants encouraged a 'biographical' approach to homecare as one that supports the person's knowledge and expertise, through awareness of their needs, preferences and personal past events.<sup>(306)</sup> A 2019 study<sup>(311)</sup> referred to this as the home representing the past, present and future that gave a sense of connection, identity and a place in the world.<sup>(311)</sup> This possibly explains why people prefer to stay living at home for as long as possible. Identity can reflect ownership of one's home and a connection to community. The home has generated nice

memories, representing a place to reflect on happy times and familiarity that represents a sense of security and comfort. It offers a freedom, for example, freedom to decorate one's own home the way one wants, a sense of self-management and staying in touch with friends in the community, including local services and clubs. Home is a reflection of self and who the person is.<sup>(311)</sup> In addition, another study conducted in Australia to explore families' experiences of home modifications for children with disabilities, identified a key theme where parents described the home as focussing on creating opportunities for their children. Subsequently, home modifications such as kitchen renovations, step ramps and grab rails created full access in the home and thus facilitated their child to participate in a meaningful life by promoting independence and self-determination in play and self-care.<sup>(312)</sup>

### 5.2.3 Autonomy

Autonomy refers to having control over one's life and day-to-day living. A study published in 2020<sup>(313)</sup> described autonomy as 'decisional' and 'executional'.<sup>(306)</sup> Decisional autonomy is the ability to make a decision independently and executional autonomy is the ability to carry out a decision independently. Homecare and support providers can support and embed autonomy as a fundamental aspect of homecare by supporting people to make their own choices and decisions.<sup>(306)</sup> In doing so, there needs to be awareness and understanding among homecare and support workers on how a loss of independence can impact on autonomy and freedom. A 2020 study<sup>(305)</sup> reported that carers who carry out tasks on behalf of the person using the service are at risk of disempowering and deskilling the person. This can be evident in cases where, for example, there is a perception that it is easier and faster if the care worker carries out the task for the person, rather than supporting them to do it for themselves.<sup>(305)</sup>

The basic need to stay independent was a strong theme identified in a study conducted in the Netherlands to explore the factors that influenced older people to use technology.<sup>(314)</sup> This study found that the participants wanted to take part in activities such as household jobs, hobbies and voluntary work and this subsequently influenced their decisions to use technology if it promoted these elements of independent living. However, using technology often required the assistance of other people, which contradicted the ethos of being independent.<sup>(314)</sup> A scoping review published in 2019<sup>(242)</sup> reported that older people who were participants from included studies continued to perform domestic duties despite challenges in doing so, in order to maintain independence, because it gave them a sense of purpose.<sup>(242)</sup> Similarly, a 2016 study<sup>(309)</sup> conducted in Australia found that participants aged between 52-91 years who were coping with terminal cancer and living alone resisted help because they wanted to hold on to their independence.<sup>(309)</sup> Other reasons

included a wish not to be a burden on their families and perceptions that their care was too much responsibility for their children.<sup>(309)</sup> Conversely, findings also noted that participants can redefine normality for themselves by accepting help and compromising, subsequently helping their confidence to maintain independence. This compromise was reflected in accepting formal homecare, so people could still live independently at home and maintain a sense of self. There was a strong wish to stay at home from all participants, with participants reporting that they lived alone by choice and not by their circumstances, thus indicating a strong want for independence and autonomy. The Embedded Practices and Intervention with Caregivers (EPIC) programme in the United States of America introduced an evidence-based coaching practice for parents or caregivers of toddlers and infants with disabilities, as a strategy to embed learning into families' everyday activities and routines with their children. This programme involves home visits that teach caregivers to promote their child's learning in order to build capacity and independence in everyday activities.<sup>(315, 316)</sup>

A study published in 2019<sup>(311)</sup> that aimed to conceptualise living at home from the perspective of older adults, identified a theme described as 'Enabling Freedom' which reflected a home that was free of constraints.<sup>(311)</sup> In addition, freedom meant being able to self-manage and personalise your own activities, having a purpose, performing those everyday tasks to live independently, and includes not having interference from others. This offered a sense of pride and personal satisfaction through achieving such tasks. Freedom facilitated a sense of self-control and autonomy over one's life and day-to-day living. In addition, a 2020 study<sup>(313)</sup> identified autonomy as an emergent theme from focus groups conducted to explore older people's experiences of domiciliary care in England.<sup>(306)</sup> Participants reported that autonomy was effected by having unscheduled visits that could impact the plans for the rest of the day, as seen by inflexible care and task-centred service delivery. This care was often perceived as rushed and carers had little time to actually chat to the person, leaving a sense of being undervalued and hindering a sense of autonomy. The authors recommended that carers allow older people to make their own choices, as this is fundamental to their well-being. Supporting a person to make choices and decisions should form an integral component of the service delivery.<sup>(306)</sup>

#### **5.2.4 Participation**

'Client-centred care' in homecare is described<sup>(317)</sup> in a 2020 review study of older persons homecare as involving the service-user in self-care and decision-making and adopting partnerships with family and carers.<sup>(308)</sup> Client-centred care applies a human rights-based approach, whereby it is underpinned by values such as a mutual respect and self-determination.<sup>(308)</sup> Care providers who fail to facilitate older people

in decision-making reflect a disrespect towards the older person.<sup>(307)</sup> A 2018 study described the concept of 'invisibility' as 'not being seen and heard as a partner in health care.'<sup>(307)</sup> This was further examined by qualitative interviews with older people and informal carers, where common themes emerged stemming from invisibility. These themes included the meaning of partnerships in health care for older people who need care and support to live as independently as possible at home, being involved in decision-making and making contributions which impact on health care and health systems. Participation encompasses decision-making and is an integral component of partnerships that generate respect and opportunities. However, participation in decision-making was reported as being dependent on the person's own resources, preferences and relationship-building. Concerns voiced from study participants included that they would offend the service provider if they disagreed with the provider's advice and hence their involvement in participation and decision-making may not be well received from the provider. Participants felt that barriers to their involvement were service providers lacking the skill and awareness to fully understand and have insight into older people's needs and preferences. Conversely, the enablers to decision-making included having appropriate information, alongside well informed decision-making. Strategies listed by participants (informal carers) relating to contributions by informal carers to improvements in practice included: maintaining effective communications and relationships with service providers; conflict resolution; organising care for family and friends including neighbours; establishing support groups; and political advocacy to improve community networking. The study showed that older people feel invisible and do not perceive themselves as partners in care and support at home. They see themselves as recipients of care and not equally involved in decision-making or making contributions to their care and support. This was attributed to service providers not acknowledging the role of the older person as a partner in health care. Participants advocated placing empowerment and partnership at the centre of healthcare.<sup>(307)</sup>

A 2020 study <sup>(305)</sup> used the term 'flexibility' to describe the extent to which a person participates in identifying their own care and support needs and thus care is tailored to meet the needs as identified by the person.<sup>(305)</sup> Low flexibility reflects a service provider having overall say in care provision that is more generic in nature, and high flexibility reflects a service that meets the needs as identified by the person. The study used a discrete choice experiment approach and found that members of the public preferred and valued greater flexibility in providing care to people with dementia, to respect autonomy and capacity for self-management. In addition, a culture needs to change to reflect this higher flexibility and tailor care to the individual needs of the person using services. There is a need to develop and improve services, taking into account the people who are experiencing symptoms of

a condition such as dementia. It cannot be assumed that a person with a chronic disease or a debilitating condition such as dementia has lost the capacity to participate in decision-making involving their care and support.<sup>(305)</sup>

An integrative literature review published in 2020 thematically analysed data from literature internationally to define 'client-centred care'.<sup>(308)</sup> A theme that emerged was client involvement and the participation of family members and care partners. The client involvement encompassed self-care, decision-making and satisfactory daily life. According to this review, a person's participation in their own care increases involvement in self-management and thus increases a sense of well-being. The client's knowledge, values, skills and cultures are included in their care and support. Empowerment is described as having active involvement. Examples provided from the included studies include participation in medication management, care planning and evaluations. The positive consequences to participation are described as facilitating clients to make decisions that are meaningful to them and give them purpose, thus enhancing autonomy and dignity in their own life at home.<sup>(308)</sup> Enhancing a client's life to feel meaningful also incorporates social relationships, including different cultural and ethnic backgrounds. This will encourage participation in social activities. Home provides a base to get out and take part in community activities and thus was a link to making friends.<sup>(311)</sup> The involvement of family and carers, be it informal or formal, offers a partnership approach to client care and builds on flexibility and good relationships. The 2020 literature review advocated that a client's involvement is at the core of a successful homecare service.<sup>(308)</sup>

### **5.2.5 Equality**

Approaches to equality in care provision have been described as giving a 'voice' to the person in their own care to bring about change.<sup>(307)</sup> Equality occurs when a person's life story, knowledge and experiences are acknowledged and respected.<sup>(307)</sup> In addition, a person should not be discriminated against because of their life story and circumstances. Homecare and support providers should create equal opportunities for all people using homecare services regardless of: age; civil status; disability; family status; gender; membership of the Traveller community; sexual orientation or religion; race, colour or nationality. In order to build respectful relationships, there is a need to be seen as a person with individual attributes and needs.<sup>(307)</sup> For example, a study conducted in the Netherlands on the utility of homecare services among ethnic minority populations reported that ethnic minorities were unable to articulate their needs and abilities, which impacted their access to homecare services. This was attributed to a language barrier, a lack of accessible information and low health literacy. The participants, aged over 50 years, in the study also highlighted that they did not always have social networks to support,

share and exchange information. However, cultural preferences to have informal carers provide home support was a strong theme among these participants.<sup>(318)</sup> A 2015 study undertaken in Canada <sup>(319)</sup> advocated the need to design and tailor interventions that will address the different needs based on, for example, gender differences, to optimise health outcomes for individuals. This study measured health outcomes using the following quality indicators: change in performing activities of daily living; cognitive function; symptoms of depression; and pain control.<sup>(320)</sup> These indicators offer a valid and reliable approach to evaluating homecare and support effectiveness in terms of keeping people healthy, safe and providing accessibility to care. In addition, the authors suggested that gender specific strategies are possibly necessary to improve the quality of care given in the home.<sup>(320)</sup>

Two studies included in the review that explored the experiences of lesbian women, aged over 60 years requiring homecare services in the United States of America (USA)<sup>(321)</sup> and Australia<sup>(322)</sup> reported a general consensus from study participants that home support workers need to listen and be sensitive to their wishes.<sup>(321, 322)</sup> Participants reported experiences of homophobia from home support workers and attributed this to: home workers coming from cultural backgrounds that disapproved of homosexuality; a lack of training for home support workers to learn about and understand lesbian, gay, bisexuality, and transgender related issues; and age of care giver, with younger caregivers being reported as less reliable and less invested in the needs of the person.<sup>(321)</sup> This resulted in participants hiding or not disclosing their sexuality to their home support workers. Subsequently, this led to a preference for lesbian care givers and to live in a lesbian community.<sup>(321)</sup> In addition, participants reported experiencing isolation from community networks and felt that if their identities were understood by the home support system and its workers, it was more likely that older lesbians would experience a feeling of being safe accessing home support services. Moreover, the study reported that many gay and lesbian people do not have family supports and hence community networks were of increased importance to them.<sup>(322)</sup> Experiences of home support services were positive among study participants in Australia, although participant numbers included were small (four participants), the quality of care was effected by a high turnover of staff. The high staff turnover resulted in repeating duties or needs to the new carer and participants reported concerns if the new carer was not lesbian or gay friendly. This exacerbated fears of discrimination and stigma about sexuality and hence increased vulnerability, as participants felt unable to express their sexuality. Participants perceived staying at home as feeling safe to live freely as a gay man or lesbian woman, which may be threatened by receiving home support. The authors suggested that service providers should implement lesbian and gay inclusive practice policies and provide training for carers to enable lesbians and gay men to feel safe and be open about their sexuality and addressing fears of a disconnect from

community. It is imperative that services are sensitive to the needs and values of the gay and lesbian population.<sup>(322)</sup>

### 5.2.6 Communication

Communication is an essential means through which service providers can demonstrate respect as part of upholding a person's human rights. In addition, communication is fundamental to providing person-centred care and support.<sup>(305)</sup> Methods of respecting an individual's needs and preferences are evident through communication, listening attentively and allowing a person to participate in their own care.<sup>(307)</sup> The Discrete Choice Experiment carried out in Ireland in 2020 captured the concept of 'personhood' and examined whether homecare services are flexible to the needs of individuals with dementia. The study included communication as an attribute and was associated with a level of engagement from homecare service providers and a person with dementia. Communication was described as the extent of getting to know the person in order to support their capabilities and preferences. The most applicable method is talking to the person about their needs, striving to maintain current abilities, holding on to connections with social networks, and enabling good decision-making to promote well-being. Enhancing communication to understand and have empathy can facilitate empowering people and supporting them to adapt to changes and engage in activities and relationships.<sup>(305)</sup>

A 2020 study<sup>(317)</sup> identified communication as a strong theme from a synthesis of how client-centred care is defined in relation to older person's homecare services. They reported that communication needs to be positive and sensitive to the person's needs, concerns and characteristics. Components of communication were described as active listening, recognition of content, interpretation, responding appropriately to unplanned reactions, and learning to say sorry. Carers need to listen attentively to the person's perspectives, respect and understand their views. Listening involves the client explaining about their lives and what matters to them. Attributes associated with professional conduct and communication include empathy, emotional intelligence, showing interest in the person and self-knowledge. Displaying these attributes will in turn facilitate people to be more open about their needs and preferences. The concept of sensitivity is discussed in this study whereby professionals need the ability to understand their client comprehensively and provide a support space to build relationships and allow the client to process negative emotions. In addition, silent listening plays a role in building a connection with the client. The concept of humour is discussed in the context of using sensitivity when interacting with an older client and displaying compassion if concerns or issues are evident. The authors suggest providing training, information and support for carers, homecare providers and family members to achieve effective communication skills that will result in an increased sense of security.<sup>(308)</sup>

### 5.2.7 Conclusion

The majority of studies reviewed considered different aspects of the experience of users, rather than providers of homecare and support services. The studies provide important insights for organisations and for regulators who seek to provide a human rights-based approach to care and support at home.

The key insights for the development of standards for homecare and support services are:

- Dignity and respect are central to providing person-centred care. Home support providers need to accept and acknowledge the values and preferences of a person.
- Equality occurs when a person's life story, knowledge and experiences are acknowledged and respected in the design and delivery of care and support services.
- A client's involvement is at the core of a successful homecare service. Supporting a person to make choices and decisions should form an integral component of the service delivery. Homecare and support providers should demonstrate how they will determine the extent to which a person wishes to be involved as a partner in their own care and to make their own care choices. The culture of homecare and support needs to change to reflect this higher flexibility and ensure that the client's knowledge, values, skills and cultures are included in their care and support plans.
- Strategies providers could use to contribute to improvements in practice include maintaining effective communications and relationships with people using services and their families or informal carers.
- Strategies that have worked well for family carers include: conflict resolution, organising care by family and friends, including neighbours and establishing support groups.
- Homecare and support providers should promote equal opportunities for all people using homecare services regardless of: age; civil status; disability; family status; gender; membership of the Traveller community; sexual orientation or religion; and race, colour or nationality.
- Providers should provide training to staff to achieve effective communication skills that will result in an increased sense of security and wellbeing for service users.

### 5.3 Safety and wellbeing

The principle of safety and wellbeing is about how health and social care services work to protect and enhance the safety and wellbeing of people who use their

services. The HIQA Standards Development Framework describes how a person should experience safety and wellbeing as follows:

*I am supported to be safe and live a whole and fulfilling life, free from harm or abuse. Services recognise that my needs and aspirations are unique and treat me as a partner when planning for my care and support. The services I use see my whole needs, not just the needs I am presenting with, and the care and support I receive helps to maintain and improve my overall health, wellbeing and development. Services work together with other services to make sure that I receive the right supports at the right time. I am supported to live a full life, to pursue my goals and to reach my potential.<sup>(2)</sup>*

### **5.3.1 Introduction**

Safety and wellbeing as a principle relates to safeguarding, the prevention of harm, and the comfort of a person while they are accessing health and social care services. It emphasises the importance of the experience of a person using services, and encourages health and social care staff to view the person as a whole, rather than focusing solely on their identified medical or social care needs. The principle of 'safety and wellbeing' emerged from the literature under two central themes:

- Quality of life and experiences
- Safety.

This section examined a range of research from primary and secondary sources. These included qualitative, quantitative, mixed-methods studies and systematic reviews. The literature relating to 'safety and wellbeing' consisted of six key publications and 12 related papers, across a range of contexts where care is delivered in the home. Such contexts included care and support of older persons, children and their families, dementia care, end-of-life care and re-ablement.

### **5.3.2 Quality of life and experiences**

The quality of life and experiences of people receiving homecare and support services emerged from the literature, under the principle of 'safety and wellbeing,' as having an impact on how people perceive care and support delivered in the home and how the lives of the person using services and their carers can be affected. Various themes emerged from the literature as having an impact on a person's quality of life and experiences, including maintaining a homely environment, social-connectedness, and ensuring people's needs are met in a holistic and person-centred way.<sup>(323, 324)</sup>

### 5.3.2.1 Maintaining the home environment

The maintenance of the home environment emerged from the literature as being an important factor when considering a person's sense of wellbeing and quality of life.<sup>(325-331)</sup> In an Australian study of maintaining the 'essence' of home during home support services, authors explored the aspects of an older person's house that make life meaningful and enjoyable. Participants in this study noted that having their own space to accommodate a wide range of activities was important to their wellbeing, including the capacity to have family and friends over to visit. Participants also valued having their own space to accommodate meaningful activities such as gardening and looking after pets.<sup>(326)</sup> This finding was also highlighted in a 2015 study of the home, where older people noted the importance of having access to local shops and transport to facilities and meaningful activities.<sup>(328)</sup>

The identity of the person receiving homecare services was found to be linked intrinsically with how they experience their home environment.<sup>(313, 326, 328, 332, 333)</sup> For example, one Australian study published in 2015 found that older people considered their home to be an integral part of their adult life and identity, having lived in their homes for 50 years or longer.<sup>(328)</sup> Similar sentiments were echoed in a 2019 study of home support services in the UK, which outlined the importance of the home as being tied to a person's identity and sense of security, and not just as a care environment.<sup>(306)</sup> One Australian study of homecare in older persons highlighted the importance of the ambience and atmosphere in maintaining the home environment where homecare is being delivered.<sup>(326)</sup> This also included being respectful of the history and emotional connections the person has with their home, and, where possible, not replacing these memories with reminders of the person's condition.<sup>(326)</sup>

The potential of homecare to increase a family's quality of life is recognised in a number of studies, including a pilot study of 35 patients in Italy which noted the safety of home chemotherapy for children<sup>(334, 335)</sup> and a feasibility study of hospital-at-home care for paediatric cancer patients.<sup>(336)</sup> However, in one study it was noted that it can be challenging to maintain a home atmosphere where medical technology intrudes.<sup>(331)</sup>

According to the findings from the literature, a person's sense of identity being tied to their home can result in challenges to care provision as the person's care needs increase. For example, again in the 2015 study of older people living at home in Australia, many participants were aware of the fact that they may have to move within the next ten years due to the challenges of living independently at home, however very few (one in five) had made plans to do so.<sup>(328)</sup> In this study, this emotional attachment made it difficult for older people to make decisions to leave their homes or make functional modifications due to challenges relating to their

age.<sup>(326, 328)</sup> The importance of 'the home' as a central aspect of a person's identity was also highlighted in a 2019 study from the perspective of the older person receiving care at home. In this study it was found that the significance of this link between home and identity was strengthened as a person's horizons became increasingly limited by mobility and physical limitations. Importantly, this study also highlighted how the concept of home is challenged by the introduction of formal carers and medical equipment, which some participants found to be intrusive and blurred the boundaries between the home and the care environment.<sup>(306)</sup>

### **5.3.2.2 Social connectedness**

Social connectedness emerged as being a facilitator towards good quality of life and experiences when receiving homecare and support services. In two Australian studies, carried out in 2010 and 2015, older people identified the local community and social connectedness as supporting wellbeing as people age-in-place.<sup>(326, 328)</sup> In the 2015 study, this was accompanied by the need to ensure the infrastructure and surrounding developments in the neighbourhood were in place to facilitate this.<sup>(328)</sup> Participants in this study also identified social connectedness as an important factor in their decision to stay in their own homes and identified the ability to invite family and friends to come visit as being highly valued. Participants in this study highlighted their connection with their neighbours, many of whom had lived nearby for decades, and noted that these connections persisted even after the neighbours had left the area.<sup>(328)</sup> In the 2010 study of older persons receiving homecare, staying close to family, friends and neighbours was again highlighted by participants as a key factor in deciding to remain at home, even as their environment began presenting new challenges to mobility and independence.<sup>(326)</sup> It recommended that efforts in maximising a service-user's quality of life should not just focus on enabling them to perform routine tasks independently within their homes, but should also focus on maintaining the social connectedness of the home. This study found that the connections with their families, friends and neighbourhoods were key supports for people ageing in place.<sup>(326)</sup>

A person's sense of control over their own life emerged in multiple studies as being central to the quality of their experience of receiving homecare and support.<sup>(324, 329, 337, 338)</sup> For example, a participant in one 2010 Australian study of homecare for older persons even highlighted that remaining in her own home was central to her sense of independence.<sup>(326)</sup> Similar findings were revealed in a randomised control trial carried out in New Zealand in 2013, which found that models of home support service delivery that are based on maximising independence can lead to significant improvements in physical function of older people ageing in place in their communities.<sup>(339)</sup> In one 2015 Australian study, it was noted that older people's perception of comfort in their home can be negatively impacted by new

developments in the area. This study recommended that older people are supported to be involved in decisions around planning and urban development, in order to avoid feelings of disempowerment and frustration.<sup>(328)</sup> A 2019 study of how older people perceive their home support services in the UK highlighted how a person's sense of ease in their own selves and their sense of autonomy could be disrupted by the changes brought about by ageing and their additional care needs, in particular changes which older people felt were out of their control. Participants in the same study noted that fears of intruders and loss of financial control due to a growing sense of vulnerability.<sup>(313)</sup>

### **5.3.2.3 Meeting people's needs in a holistic way**

The perception of having unmet care needs was found in multiple studies to have a negative impact on how people experience home support services.<sup>(329, 338, 340-342)</sup> For instance, one 2014 study of Canadian homecare highlighted that older adults whose formal care needs were being met had significantly higher levels of life satisfaction, and lower levels of loneliness and stress compared with older adults whose homecare needs were not being met.<sup>(343)</sup> In a 2014 systematic review of palliative homecare, it was found that unmet spiritual needs could impact the quality of life and experiences of the person receiving care and support at the end of their life. This also extended to carers, whereby fear of not being able to attend religious services and fulfil the spiritual needs of the person in care was highlighted in many of the papers included in this review.<sup>(343)</sup> This was also highlighted in the findings from a 2014 systematic review of palliative homecare, which identified practical unmet needs for carers and service-users in areas such as assistance with equipment, occupational support, household tasks, and support with child-minding.<sup>(338)</sup> The same review also highlighted financial assistance as being an area of unmet need that had a negative impact on how people experience their care. Additionally, one systematic review of palliative homecare identified psychosocial needs as being more frequently neglected than physical needs.<sup>(338)</sup>

Various methods to improve quality of life and wellbeing also emerged from the homecare literature.<sup>(342, 344-346)</sup> For example, one Swedish study found that meaningful daily occupations from occupational therapy services in the home can benefit people with severe psychiatric disability.<sup>(344)</sup> Another Swedish study on family members' lived experience when a sick child received homecare from primary healthcare services highlighted that the receipt of homecare helped to strengthen family life and promote health in families with acute, long-term and palliative care needs.<sup>(346)</sup> A further benefit of a holistic approach emerged in a 2020 English study on homecare for people with dementia, where it was found that a collaborative care-planning approach with family members had significant benefits in terms of the wellbeing of the person receiving care and support. This study highlighted the

importance of including the family or informal carers in the homecare and support relationship to achieve the best outcomes for the person.<sup>(345)</sup>

The convenience of home-based rehabilitation for patients requiring complex care is an important factor in improving quality of life. A systematic review and meta-analysis of home-based rehabilitation on improving physical function of patients with a stroke showed positive outcomes, though it highlighted how individual patient characteristics can significantly affect improvements in daily functions.<sup>(347)</sup> This person-centred focus is echoed in a 2014 narrative review which demonstrates the need to pay attention to and discuss patients' psychosocial issues in addition to routine monitoring of medical and physical problems.<sup>(348)</sup> Focusing on patients receiving home parenteral nutrition (HPN), it identified several interventions that can improve patient outcomes, quality of life and financial distress, including patient education, support groups and treatment of symptoms such as depression and fatigue.

It was found in the literature that a person's behaviour can change in a way that negatively impacts their quality of life when their homecare and support needs are not being sufficiently met.<sup>(328, 349)</sup> In a 2015 Australian study of older people living at home, participants noted that they had noticed behavioural changes as a result of difficulties they were experiencing. For example, participants noted difficulties in heavy housework such as gardening and cleaning gutters, and noted that they had begun avoiding hobbies that could result in strenuous activity.<sup>(328)</sup>

The relationship of the person receiving care with their formal carer was also identified as having an impact on how people experience their care.<sup>(350)</sup> This was particularly evident in one 2014 UK study which noted that the formal care relationship provided a 'special friendship' while at the same time providing respite to informal carers.<sup>(343)</sup> The timing of visits should also be considered. One 2019 study of homecare for older persons highlighted that an ill-timed visit from a formal care worker could disrupt the service user's entire day.<sup>(306)</sup> Additionally, if people were treated in a manner they perceived as being 'demeaning' with lack of regard for the persons individuality, then this resulted in de-personalised care.<sup>(306)</sup> This study highlighted that just because care is delivered in the home does not mean that it should immediately be assumed to be 'person-centred' without regard for the individuality of the person.<sup>(306)</sup>

### 5.3.3 Safety

Safety emerged from the literature, in the context of homecare and support services, as the prevention or reduction of harms that may be caused by a person's disabilities or advanced age.<sup>(180, 325, 333, 351-354)</sup> Homecare and support services were identified across the literature as being important for the prevention, early identification and

management of conditions which may threaten the safety and wellbeing of at-risk populations.

Primarily, safety in the home setting can be supported by the people delivering homecare and support. A study undertaken in Norway of challenges in quality and safety work faced by homecare managers identified many contextual factors, including lack of continuity of care due to sick leave and the impact of continuous change processes.<sup>(351)</sup> A 2021 study highlights the importance of infection prevention and control in community nursing, while another 2016 study points to the importance of training to deal with patients with complex devices, in order to provide the same level of care that they received in hospital.<sup>(180, 353)</sup> The role of prevention is underlined by a study of how health professionals screen for vulnerability in older people in community and in home settings.<sup>(352)</sup> Similarly, a 2013 Canadian study highlighted shortfalls in promoting the health and wellbeing of older adults. This study noted that homecare interventions in Canada were focused on short-term solutions and reducing heavy reliance on acute care. This meant that services were allocated on the basis of physical or medical needs of the person receiving care and support, as opposed to their wider social and wellbeing needs. As a result, the best overall health and wellbeing outcomes for the person receiving care and support at home were not always met.<sup>(355)</sup> The need for both healthcare practitioners and informal caregivers to follow best practice in delivering medical care at home is highlighted by guides on long-term ventilation and nasogastric feeding,<sup>(356, 357)</sup> while effective education of caregivers is recognised as an important feature of safe homecare.<sup>(357-360)</sup>

Physical safety can emerge as an issue following hospital discharge and transition of care to home. An American study from 2020 explored how the use of discharge data on pain in heart failure patients could be used as a key indicator for clinical focus for these patients in the home setting.<sup>(361)</sup> A Danish study on follow-up of frail elderly patients found that a structured programme undertaken by GPs and district nurses could reduce hospital readmission and improve medication control.<sup>(362)</sup> Additionally, a 2017 systematic review demonstrated that nurse-led and nurse-collaborative interventions can improve medication adherence among discharged older adults.<sup>(363)</sup> Similarly, a 2017 study of older people receiving low-intensity home support services in North Dublin found that levels of frailty (according to the Clinical Frailty Scale) correlated with greater number of home help hours and greater difficulty with communication. This study recommended incorporating frailty measures into community supports and re-ablement in order to detect and prevent deterioration at an early stage.<sup>(364)</sup> A Norwegian study also highlighted that COPD patients who received early discharge to a 'Hospital at Home' programme felt safe, having

received information that was adapted to specific situations in their daily lives and given in a familiar environment, with positive impact on their self-management.<sup>(333)</sup>

It emerged from the literature that a person's feelings of safety within their own home can be challenged by the vulnerability associated with the need to access home support services, in particular home modifications or assisted living.<sup>(331, 334, 346, 365)</sup> For example, it was highlighted in one Australian study that visible home modifications may signal to opportunistic intruders that the resident is a vulnerable person who may not be able to defend themselves. People were also concerned about how home modifications would make them appear to their neighbours, and whether it would draw attention to the fact that they are vulnerable or lead to exclusion from the community.<sup>(326)</sup> It should be noted that while home modifications may be necessary for some people to ensure their safety while living at home, some people cannot afford the cost of installing them, and this may result in safety issues. For example, one Australian study in 2015 highlighted that many older people cannot afford to make adaptations to their homes as a result of having lost funds during the recession.<sup>(328)</sup>

In some instances the mental wellbeing of the person receiving homecare and support services may present a threat to their own personal safety, and therefore it emerged from the literature that professionals engaged in the delivery of homecare services should be able to identify patterns and risk factors associated with intentional self-harm or suicidal behaviour in their clients.<sup>(337, 366, 367)</sup> A 2020 mixed-methods study on homecare in the USA identified depression in their older clients whose care needs were not being met, and these symptoms included loss of pleasure in activities, sleep changes, mood changes, sadness, loss of appetite and withdrawal from engagement with health and social care professionals.<sup>(366)</sup> One Canadian study in 2015 explored patterns of intentional self-harm in older homecare clients who were considered at-risk for suicide-related behaviour. Those at-risk included older men (60-74 years old) who had a history of mental illness, substance abuse or alcohol use disorder, or those taking medication for a psychiatric diagnosis.<sup>(368)</sup> The same study highlighted that mitigation of these behaviours includes knowledge of how to prevent them, for example by having positive social relationships, in both older men and older women. Interestingly this study found that advanced age and functional impairments in activities of daily living (ADL) were protective against self-harm after adjusting for other risk factors.<sup>(368)</sup> It was recommended in this study that suicide prevention strategies should focus on increasing opportunities for social relationships among homecare clients.<sup>(368)</sup>

Communities and social relationships with neighbours were identified as being important protective factors for older people's safety and wellbeing. In one Australian study, participants noted that they felt safe leaving their homes as they

could trust their neighbours to look after their houses while they were gone. Participants in this study also noted giving spare keys to neighbours in case of emergencies and highlighted the importance of checking in with each other if they had not seen their neighbours in a few days. Living in a cul-de-sac, close to friends and community activities was also identified by participants as creating a sense of safety.<sup>(328)</sup> In a 2013 UK study of older people with assisted-living needs, many participants reported being prepared to risk their own safety in order to achieve what mattered to them, such as hobbies and other meaningful activities, despite conflicting advice from their families and professionals involved in their care.<sup>(296)</sup> This highlights the importance for homecare services to include supports for social activities and hobbies and service user choice.

Loneliness and social isolation were identified in multiple studies as being barriers to the safety and wellbeing of people receiving homecare services, particularly older people.<sup>(242, 296, 329, 368)</sup> One systematic review highlighted that as people began to experience limitations as a result of their physical or mental health or due to advancing age, they often lost the ability to sustain social relationships. Such limitations included sight loss, hearing loss, difficulties with memory or being unable to travel to do things that they used to enjoy doing. These resulted in the person's isolation but also meant that people become increasingly dependent on their close relatives and carers for daily socialising and mental stimulation.<sup>(242)</sup> Again, this highlights the importance for homecare services to meet social needs of service-users. The same review also found that, as a person becomes more dependent on their family and their social circle becomes smaller, more people report feelings of being treated in a patronising way. Interestingly, it was highlighted that people being cared for at home report being perceived differently after periods of increased vulnerability, such as after a fall or an illness.<sup>(242)</sup>

Social isolation as a barrier to a person's safety and wellbeing was also highlighted in a 2013 UK study on what matters most to older people with assisted living needs. While some participants in this study reported being satisfied with a small social network, some were extremely lonely. Some older people in the study actively resisted contacting their family as they felt like a 'burden' on their families lives.<sup>(296)</sup> People in this study also reported feeling anxious about being forgotten about or abandoned, both by their families and by their professional carers. Where clients exhibit self-neglecting behaviour, as one 2010 Irish review illustrates, this can result in legal issues for the public health nurse in Ireland. This review highlights the need for an approach that addresses both the nurse's professional responsibility and the client's rights in a balanced way, fostering trust and support.<sup>(369)</sup>

### **5.3.4 Conclusion**

Safety and wellbeing in homecare and support services emerged from the literature under the themes of 'quality of life and experiences' and 'safety.' Further examination of the theme 'quality of life and experiences' revealed the sub-themes 'maintaining the home environment,' 'social connectedness' and 'meeting people's needs in a holistic way.' Characteristics of good person-centred care delivered in the home emerged under the first theme as respecting the home of the person and ensuring minimal disruption to this environment, where good memories and experiences are not replaced by memories of being unwell, or feeling unsafe. It was found that the ability to remain connected to neighbours, friends and family has a positive impact on both a person's safety in their home and their overall wellbeing, and people should be supported to remain active in their communities where this is possible. It emerged that good, person-centred homecare services should meet the needs of the person in a holistic way, and not be overly restricted by task-oriented care plans or issues with timing. Lastly, it emerged that the safety of the person in their home can be supported by preventing loneliness, being aware of signs of decline in a person's mental wellbeing, and focusing on preventative measures to reduce risk of acute illness or injury.

## 5.4 Responsiveness

The principle of responsiveness includes both how health and social care services are organised to deliver coordinated care and support that meets the needs of people using their service, and how people working in these services identify, assess and respond to a person's needs in day-to-day practice. The HIQA Standards Development Framework describes how a person should experience responsiveness, in the services that they use, as the following:

*I receive care and support from skilled, experienced and trained staff who are clear about their role and responsibility in my care and support. These staff respond to my individual needs and circumstances in a timely and sensitive way and are informed by the best available evidence and information. Staff take the time to get to know me and see my needs, preferences and goals in a wider context, and do not focus on only meeting my most urgent needs. All staff involved in my care and support work together within and between services so that I receive the best possible care and support and they are supported to do this by the services they work in.<sup>(2)</sup>*

### 5.4.1 Introduction

The principle of 'responsiveness' emerged from the literature as the way in which health and social care staff respond to a person's needs, and how their abilities, duties and competencies facilitate this. Health and social care staff, in this instance, refers to any person employed in delivering care and support to a person in their own home, and includes, for example, homecare workers, personal assistants, health and social care professionals and home nursing. Responsiveness as a principle is intrinsically linked with the concept of person-centredness, where responsive care puts the person receiving care and support first, at the core of everything that health and social care staff do. Responsiveness is facilitated by the daily work of individuals, but should also be ingrained in and supported by the culture of homecare and support services organisations. This section on responsiveness will focus on the ways in which health and social care staff facilitate responsiveness in their daily work, which emerged under the following themes:

- Professional duty and competence
- Communication
- Collaboration.

These themes, and how they emerged from the literature across various contexts in homecare and home support services, will be discussed in the following section.

This section examined primary and secondary research, including qualitative, quantitative, mixed methods studies, and systematic reviews. These consisted of 12 key publications, with an additional 16 papers covering a range of contexts of care delivered in the home. Such contexts included care and support for older persons, re-ablement, dementia care, interaction of home support services with informal care, palliative care, personal care and home nursing care.

### **5.4.2 Professional Duty and Competence**

Professional duty and competence emerged as a key theme under the principle of responsiveness, and described the importance of having the skills, qualifications and approach or outlook needed to carry out responsive care and support in their daily work. This theme can be broken down into three sub-themes:

- Competence and skills
- Expectations
- Time.

#### **5.4.2.1 Competence and skills**

Competence and skills emerged as a sub-theme from the literature, and it was found that these could be supported on an organisational level by encouraging health and social care staff to be constantly learning and self-reflecting in their daily work.<sup>(370-372)</sup> A 2020 Dutch study on re-ablement describes the perception of skills from the point of view of the homecare worker, where many indicated that they had skills in re-ablement but that they were unable to apply certain aspects of their training due to time constraints or a perceived lack of added value to the person using the service. On the other hand, homecare managers and supervisors attributed this to a lack of self-reflection, insufficient communication, and a misconception that they had already sufficiently mastered these skills.<sup>(373)</sup> A 2013 study on Norwegian homecare found that competence could be supported by an emphasis on regular educational courses and training.<sup>(374)</sup> A 2010 British study on the long term effects of home-based re-ablement supported these findings, recommending that staff undergo regular training and ongoing supervision to support independence of people using services and also to ensure more cost-effective care at home.<sup>(375)</sup>

Continuous learning and maintenance of skills are also facilitators of responsive care, for example, regular and specialised training on medical devices,<sup>(376)</sup> support to deliver paediatric palliative care,<sup>(377)</sup> or simple interventions to manage mild conditions.<sup>(378)</sup>

A 2019 study on stressors for homecare workers in the UK found that working with underqualified colleagues resulted in additional demands to their own workload. Participants noted that the shortage of domiciliary care workers, coupled with a lack of qualification requirements for the role, leads to employees being recruited at short notice without proper examination of their competence and skills, and without providing sufficient training or induction to their role.<sup>(379)</sup> In this study, participants highlighted that lack of training results in high staff turnover, a breakdown in continuity of services, and a reduction in the quality of care provided to people in their homes.<sup>(379)</sup> The authors of one 2015 American study on workplace violence reported a relationship between higher confidence to prevent and respond to violence as impacting positively on reducing burnout and stress.<sup>(380)</sup> Women who experienced any type of violence experienced negative health outcomes such as work burnout, stress, depression and sleep problems. Moreover, a fear of, or a perception of threat of experiencing a type of violence negatively impacted health outcomes for homecare workers. The authors also highlighted that research studies have linked increased staff turnover to workplace violence.<sup>(380)</sup>

The principle of responding to the needs of the child with appropriate care is reflected in a number of studies, from recognition of the value of participation in home, school and community life, to youth living with disabilities,<sup>(381)</sup> to the benefits of both residential treatment and at home treatment for children and youth with severe mental health problems.<sup>(382)</sup> Adaptation in order to provide timely and appropriate services is important; for example, a 2012 study showed the usefulness of adopting a telehealth model of delivering early intervention services at home in rural and remote areas.<sup>(383)</sup>

#### **5.4.2.2 Expectations**

The expectations of the people receiving care and support in their homes emerged as a sub-theme from the literature. A 2013 study on Finnish homecare highlighted that people expect good professional competence from their homecare workers, and believed that high worker competence would further the quality of care that they received.<sup>(384)</sup> In a 2020 study on homecare in Australia, people receiving homecare expected that services would be delivered to them in a reliable way, with sufficient collaboration and organisational support to ensure continuity of care.<sup>(385)</sup> This study also found that team work, responsiveness, and completion of daily work to a high standard were appreciated by service-users.

On the other hand, the service-user's expectations of what tasks a homecare worker should complete during their visits could occasionally be inappropriate or unreasonable, for reasons ranging from management rules, and the legality of the

tasks being requested.<sup>(370, 386, 387)</sup> One 2020 study of homecare in the USA found that homecare workers were occasionally asked to perform tasks beyond the scope of their regular duties, such as home improvement, window-cleaning, or were occasionally asked to repeat tasks such as cleaning if they weren't done to a high enough standard.<sup>(386)</sup> Respondents revealed that if they complete the task once, there is an expectation that they will do it again, or that other homecare workers will be expected to do the same.<sup>(386)</sup>

Planning and organisation emerged as useful tools for addressing conflict around unreasonable expectations of tasks that a homecare worker can carry out.<sup>(370)</sup> The same study on homecare in the USA found that a written care plan, where tasks were specifically and purposefully laid out, could be provided by homecare providers, to offer a shared understanding between the service user, homecare worker and the provider as to what tasks are inappropriate.<sup>(386)</sup> This study revealed that such a tool may also alleviate feelings of blame when the homecare worker has to say no to a service-user. On the other hand, other sources in the literature criticises such a task-minded approach. For example, a 2020 study on homecare in Australia found that people using services were critical of the 'one-size-fits-all' approach taken by homecare management, and reported that staff focused more on completing certain tasks rather than doing what was asked for.<sup>(385)</sup> A 2013 randomised controlled trial on nurse-led homecare in Canada reported success in using standardised, evidence-based tools coupled with a person-centred approach focusing on prevention strategies tailored to individual needs.<sup>(355)</sup> Therefore this suggests a balance should be sought, in order to set reasonable boundaries and alleviate concerns on all sides of the care relationship. The importance of a patient-centred, responsive relationship with continuity of care was demonstrated by an evaluation of Canada's Expanding Paramedicine in the Community (EPIC) programme, a partnership between primary care and community paramedics to provide home support for those with chronic disease.<sup>(388)</sup>

Familiarity with the people in a person's care is a facilitator of responsiveness; a questionnaire completed by 490 homecare clients and professionals in Finland identified disparities in their perceptions of clients' wellbeing and the care received, pointing to a need to provide a service that meets the client's own perceptions and needs.<sup>(389)</sup> Other studies have highlighted the importance of a partnership approach with the client or patient,<sup>(390, 391)</sup> for example, in building and maintaining a patient-centred working relationship to prevent worsening disability,<sup>(392)</sup> or changing health and social care professionals' attitude to stroke self-management.<sup>(370)</sup> Building good relationships should also extend to the close relatives of those receiving care; a 2020 Danish study points to the need to identify and test interventions in clinical practice supporting relatives during the course of a long disease.<sup>(393)</sup>

### 5.4.2.3 Time

Time emerged as a significant sub-theme under professional duty and competence.<sup>(376, 384, 394-396)</sup> Timing of homecare visits was found to be crucial to the satisfaction of the person using the service, and a poorly-timed visit or missed appointment could have negative impacts on the person's day and their continuity of care.<sup>(384)</sup> On the other hand, it was found that homecare workers face significant time constraints in their daily work, and often struggled to complete tasks within the agreed time frame.<sup>(371, 395)</sup> This theme was highlighted in a 2013 study on Norwegian homecare, which attributed rapid changes in the health and social care system, decreasing resources and increasing workload for the time constraints faced by staff. This study emphasised that providers should have consideration of the continuous need for the tough prioritisation that staff need to carry out as a result of such time constraints, and should take appropriate measures to prevent staff burn-out.<sup>(374)</sup>

A 2020 study on homecare in Norway found that time constraints place limitations on how involved staff could be with the person using the service, for example they could not sit down for a coffee or a chat if they were in a rush to their next appointment, or if organisational rules specifically forbids such engagement.<sup>(394)</sup> A 2020 study on homecare in Australia found that, not only were time constraints resulting in limitations on what tasks could be completed, but that this was coupled with inefficiency, so service-users were not receiving the full extent of the scheduled care set out in their care plan.<sup>(385)</sup> A 2013 Finnish study suggested that the quality of homecare can be ensured by allocating adequate time and proper timing to homecare visits, and that changes in staff should be minimised in order to maximise the continuity of care.<sup>(384)</sup> Similarly, a 2015 study on homecare in Canada found that homecare workers believed that time constraints could compromise the overall quality of care that people using services receive.<sup>(397)</sup> A 2021 Irish study in older persons with dementia found that high informal care hours, along with unmet formal care needs, was a predictor of admission to long-term care, and highlighted the need to focus more on the quality of care hours provided, as opposed to the quantity of hours.<sup>(398)</sup>

Time also emerged in terms of zero-hour contracts and travelling from one visit to another.<sup>(379, 396)</sup> A 2019 study on homecare work in the UK reported that homecare workers often had very short visits with people using services, with large gaps in-between, for which they were not paid. This meant that homecare workers were only paid for a small number of hours despite being out for the entire day.<sup>(379)</sup> The same study found that this issue was confounded by low wages in the majority of respondents. Homecare workers reported that their role was extremely important for

people using services and for wider society, but at the same time they were struggling to pay bills and support their own families, despite having a job with such a high degree of responsibility.<sup>(379)</sup> This was highlighted particularly during the COVID-19 pandemic, according to a 2020 Irish study on homecare workers for older people, which recommends recognising homecare workers as crucial health and social care staff and protecting their income in the event of their absence due to sickness or the need to self-isolate.<sup>(399)</sup>

### 5.4.3 Communication

Communication in this context focuses on the ability of health and social care staff to speak openly and transparently with the people, and the families of people they provide homecare and support services to.

In situations where there is a language barrier between the person receiving care and support at home and the homecare worker, communication may be eased by using an interpreter. However, this presents additional challenges, as described in one 2012 Swedish study in a homecare context.<sup>(400)</sup>

This study found that challenges arise when the interpreter is expected to know medical terms, and concepts that go above and beyond their role. Additionally, it is important for the interpreter to remain neutral, without engaging in conflicts between the homecare worker and the person receiving care and support. There are also threats to confidentiality when more personnel are required, where the particulars of a person's medical history are concerned. This study recommends that the interpreter should be a distinct role, separated from the care provider and not viewed as 'teaming up' with either the client or the homecare worker.<sup>(400)</sup>

Advocacy was identified as a facilitator of good communication between health and social care staff and people receiving care and support at home, and may help to bridge gaps in communication. A 2012 study on language barriers in homecare in Sweden highlighted that advocates can draw the homecare worker's attention to cultural differences, and allow homecare workers to understand what is essential and important in the discussion with the person receiving care and support.<sup>(400)</sup>

According to a 2020 study on homecare in Australia, when communication practices are poor on an organisational level, this contributes to poor communication between homecare workers and people receiving care and support at home. Poor communication, in this instance, lead to the routines of the person receiving care and support frequently being disrupted as a result of changes and lack of continuity in the care workers visiting their homes.<sup>(385)</sup>

A 2013 study on homecare after hospital discharge in Norway found that good interdisciplinary communication between health and social care staff involved in discharge planning was key in arranging the provision of care and support at home. The same study identified gaps in communication between the hospital and the home support services provider, with communication being 'insufficient' or 'lacking' in places.<sup>(374)</sup>

Communication with the family of the person receiving care and support at home was identified as being a factor in facilitating responsiveness. This meant involving family in decisions around the person's care, and being mindful of the role that families play in providing care and support while the homecare worker is not there. A 2013 study on homecare after hospital discharge in Norway identified family as being a rich source of information for planning a good transition to the home, in particular the person's next-of-kin, who often knew the person's situation better than anyone else. This study also noted that the opinions and needs of the families occasionally differed from that of the person being discharged to homecare, where families occasionally had unrealistic expectations about the possibilities for care and support provision. This study recommended that such situations are resolved through communication, involvement and cooperation with the person and their family.<sup>(374)</sup>

The need for service providers to have good communication with parents of children receiving care and support at home is shown in an Australian study of contrasting perspectives on respite care.<sup>(401)</sup> Similarly, a focus group study highlighted family relationships with care providers as being critical in supporting the transition from hospital to home.<sup>(402)</sup> Trust has been identified as a central element of this relationship.<sup>(403)</sup> While a practical intervention such as a post-discharge phone call from a nurse to address any issues in transition of care was shown in an American pilot study to be effective in reducing confusion or difficulty.<sup>(404)</sup>

Gaps in communication can lead to problems in creating a smooth, comfortable experience for the person receiving care and support at home, particularly where transitions from hospital to home are concerned. A 2013 study on homecare after hospital discharge in Norway found that factors contributing to poor communication included a lack of routine, and not having a dedicated forum for communication between homecare providers and the hospital.<sup>(374)</sup> This study recommended focusing on furthering knowledge and insight into each group's role in the discharge process, in order to identify communication gaps as they arise. Furthermore, the implementation of formal processes, such as guidelines and communication systems could be helpful.<sup>(374)</sup>

Communication is limited by the nature of the lone-working role of a homecare worker. This was highlighted by one Dutch study in 2020 which found that opportunities for homecare workers to discuss challenges in providing care and support to people in their homes were few and far between, as they have little contact with their colleagues.<sup>(373)</sup>

#### **5.4.4 Collaboration**

The ability to work as part of a team in homecare or home support services was identified as an important factor for staff in collaborating, and collaboration should be supported by robust organisational processes. One 2020 study carried out in Norwegian mental healthcare delivered in the home found that health and social care staff were often quite self-critical about their skills in consistency or continuity in work when collaborating, and this was exacerbated by a lack of information and training<sup>(394)</sup>

The importance of practitioners' familiarity with individual families and of supporting family-centred care is highlighted in a number of studies. One 2011 study in particular showed that the long-term outcomes of children with severe mental health issues were impacted by family relationships, whether the children accessed residential care or home treatment.<sup>(382)</sup> In one 2013 study, a correlational study of caregiver burden, parenting style and sibling relationships in families of children with disabilities, advised that providers should take a family-centred approach that encourages positive parenting and sibling relationships. A Dutch study of the actions, challenges and needs among parents supporting the participation of children with a physical disability similarly points to the responsibility of practitioners to build the knowledge needed to support parents.<sup>(405)</sup> However, a Canadian study of 538 families raising children with disabilities sounded a note of caution in recruiting parents to implement home-based therapy regimes, finding that this can tax family resources.<sup>(406)</sup>

It was identified in the literature that collaboration could be negatively impacted by disagreements or conflict between homecare workers, informal or family carers, and people receiving care and support. A 2020 study on collaboration in mental health homecare in Norway found that disagreements between homecare staff and people receiving care and support at home and their informal carers largely originated from unspoken expectations on either side, thus highlighting the importance of communication in a collaborative care relationship.<sup>(394)</sup> This study recommended that homecare staff set boundaries with the person receiving care and support at home, without hiding behind their 'titles' or using their position of authority to resolve

disagreements. Where disagreements persist, this study recommended that providers step in, particularly if the situation is very challenging.<sup>(394)</sup>

Where there are disagreements, having a strong collaborative relationship can support professionals to make decisions around care and support delivered in the home. A 2020 study carried out in the United States found that simply the awareness of being part of a bigger work team could help homecare workers assert themselves in challenging situations.<sup>(386)</sup>

Participants in a 2020 study on consumer expectations of homecare in Australia highlighted that the collaborative relationship could breakdown when staff were unreliable, or lacked respect for the personal belongings of the person receiving care and support at home.<sup>(385)</sup> On the other hand, professionals who were honest, kind, genuine and trustworthy could offset the negative feelings participants had about how their care is organised. These negative feelings tended to come from inefficiency, poor communication processes, high staff turnover and service limitations within the provider organisations.<sup>(385)</sup>

A 2013 study on homecare of older persons in Finland found that people receiving care and support at home expected staff to have a positive approach towards work. This meant that homecare staff were expected to be understanding, respectful, accepting, and interested in the person they were caring for.<sup>(384)</sup> Similarly, a 2020 study, also in Finland, found that homecare workers found it easier to carry out their work when they were interacting with more positive clients.<sup>(394)</sup> In both studies it was found that the emotional climate was key in supporting the care relationship between the professional and the person receiving care and support at home and their families.<sup>(384, 394)</sup>

A 2020 study on homecare in Australia highlighted staff values that were important for good care relationships, such as being honest, trustworthy, genuine, kind and caring, and displaying good communication skills and competence.<sup>(385)</sup> On the other hand, service users in this study were dissatisfied with the poor communication that occurred as a result of poor internal processes within organisations.<sup>(385)</sup> This study found that interacting and collaborating with highly valued staff could alleviate people's frustrations with how their homecare services were organised. Agreeing with this, a 2020 study identified flexibility and personalised communication as being highly valued by people receiving homecare in Ireland.<sup>(305)</sup> According to one 2015 review on integrated care in the home, the research suggests that integrated care is associated with greater client satisfaction, increased use of community based services, and reduced hospital days, however the authors of this review noted there is lack of research examining impact of integrated care on persons with dementia and their carers.<sup>(407)</sup>

The role of an integrated or cross-sectoral approach in care and support was highlighted in a scoping review on tailoring healthcare to patients with long-term tracheotomies.<sup>(408)</sup> Its results indicate beneficial effects on patient-related outcomes, care coordination, healthcare use and costs. A qualitative study undertaken in New Hanover in the US similarly demonstrated that a collaborative care model to improve transitions of care reduced hospital readmission for heart failure patients.<sup>(409)</sup> Health guidelines are also important in delivering safe care, as highlighted in a descriptive, multiple-case study on improving care of venous ulcers at home.<sup>(410)</sup>

Good relationships are also identified as imperative in delivering responsive palliative care. Interviews conducted with 42 parents in the Netherlands found that parents of children in palliative care need healthcare professionals who understand and carefully handle their worries, losses, parent-child relationship and coping strategies.<sup>(411)</sup> The need for healthcare professionals to have up-to-date knowledge and skills, and to engage in collaborative working, are also to the forefront in palliative care. A 2010 qualitative study of the experience of community children's nurses and palliative care nurses in the UK, pointed to the challenge faced by many community nurses in maintaining their skills, given the relative rarity of childhood cancer.<sup>(412)</sup> A pilot study of a successful hospice at home programme also pointed to the usefulness of enhanced clarification of roles, enhanced access to multi-disciplinary services, greater communication across services and improved information provision.<sup>(413)</sup> That need for inter-professional collaboration in home palliative care was similarly anticipated in one 2011 study, particularly the need to engage GPs with the work of community nurses.<sup>(414)</sup>

A 2013 randomised control trial on a nurse-led model of homecare for older people identified inter-professional collaboration as being critical to the success of the intervention. In this study, collaboration between professionals on the care team fostered information-sharing and coordination with homecare providers, leading to the development of evidence-based care plans that presented the expertise of all members of the team in a balanced way.<sup>(355)</sup> This study highlighted that the identification of a clearly defined case-manager facilitated this strong inter-professional collaboration. Inter-professional collaboration in homecare and support services could be hindered by lack of information-sharing, particularly in interdisciplinary care teams. A 2013 study on Norwegian discharge-planning described homecare for psychiatric patients, who were often highly vulnerable, as being negatively impacted by poor collaboration and insufficient communication between psychiatric nurses and homecare workers.<sup>(374)</sup> Homecare workers in this study felt ignored by the psychiatric nurses, who were unwilling to share

information, because of concerns around patient confidentiality, and this was perceived as problematic and frustrating.

The literature also described the barriers that professionals face in collaborating with people receiving care and support at home. A 2019 UK study on stressors for domiciliary care workers highlighted that working with service-users and their families who are violent, rude or aggressive was very stressful.<sup>(379)</sup> While the participants of this study had grown somewhat accustomed to these conflicts as part of their daily work, they still found it difficult to deal with and described potentially benefitting from further support from management within their organisation. A 2020 Dutch study highlighted that collaboration in re-ablement could break down when service-users are unwilling, or when older people have become accustomed to not being physically active.<sup>(373)</sup>

#### **5.4.5 Conclusions**

Responsiveness emerged from the literature under the key themes of professional duty and competence, communication and collaboration. Further examination of the theme 'professional duty and competence' revealed sub-themes, such as skills, time and expectations. According to the literature, characteristics of responsive homecare and support services include competent health and social care staff who are skilled and who collaborate and communicate openly with families and people receiving care and support to bring about the best outcomes. Importantly, responsive health and social care staff should have enough time to carry out holistic, person-centred visits and should be able to time their visits around the schedule of the person and their families. Collaboration and good communication emerged as important characteristics of responsive homecare and support services, where these can support continuity of care and homecare worker job satisfaction when the appropriate processes are in place. Lastly, the expectations of the person receiving care and their families should be respected, where both parties have an awareness of what a responsive homecare service can and cannot do. Homecare workers should be supported by their organisation to safely meet the expectations of service-users and their families.

## 5.5 Accountability

The principle of accountability is the foundation for how health and social care services ensure that people receive high-quality safe care and support that is consistent, coordinated and focused on achieving good outcomes for them. The HIQA Standards Development Framework describes how a person should experience an accountable service as follows:

*I receive safe, consistent and high-quality care and support. I know who is responsible for delivering my care and support and I have confidence and trust in the health and social care services I access. The services I use are well managed and everyone knows and understands their roles and responsibilities and there is a culture of open communication, learning and reflection, and improvement. I have access to the care and support that I need and services work together to provide me with high-quality, coordinated and safe care and support and to make sure that I do not experience any gaps in my care and support.<sup>(2)</sup>*

### 5.5.1 Introduction

An accountable homecare and support service aims to ensure that service users receive high-quality, safe care that is consistent, coordinated and focused on supporting people to live at home safely, minimises the decline of health and function, increases independence, and promotes quality of life<sup>(372, 415)</sup>. To achieve that, accountable homecare services should have a clear vision for their work. They should support their staff to deliver on this vision, work well with other relevant services, and regularly assess the impact of their work on those they are caring for and supporting<sup>(379, 416, 417)</sup>

The systematic review of the literature found 21 primary publications and 42 secondary papers. Additional targeted searches identified 13 papers relating to the principle of 'accountability'. Across the primary publications, nine were qualitative studies, five quantitative, five mixed-methods and two systematic reviews. The majority of studies included in this section were focused on homecare workers and managers (seven), integration and transition care (nine), and the quality of care provided (ten) by homecare organisations. These studies reflected the role of an accountable homecare service to ensure that the service user receives a high quality of safe, consistent, and coordinated care. The studies included care and support of older persons, dementia care, people with disability, children, complex care, end-of-life care and re-ablement.

This principle of accountability is divided into the following subheadings:

- leadership and governance
- collaboration and integration between homecare, and health and social care services
- quality of care provided
- sustainability.

Leadership plays an essential role in the accountability of homecare services. Managers and supervisors are responsible for coordination and quality of the care and support provided, ensuring that the service is complying with relevant legislation and regulations, standards and guidelines, and is operating under service level agreements or contracts, to ensure that service users are safe and that their needs are met.<sup>(374, 418-421)</sup>

Collaboration and integration between homecare providers, hospitals and primary and community health and social care services is essential to meet service user's care expectations.<sup>(374)</sup> An accountable homecare service ensures that the information management systems are in line with a governance framework, are reliable, secure and shared in a timely and appropriate manner to reduce risks throughout care and facilitate homecare staff to meet the needs of each service user.<sup>(419)</sup>

Research has shown that in an accountable homecare service, quality care and support are delivered on a daily basis.<sup>(397)</sup> High-quality care extends beyond the completion of individual personal, medical and household tasks. It involves consistency and continuity of care and support and development of trusting relationships between homecare providers and service users.<sup>(397)</sup> An accountable homecare service involves service users in decision-making, supporting their autonomy, control over their own care and support, and dignity.<sup>(397)</sup> Assessment and re-assessment procedures enable homecare providers to better respond to changes in service user's needs and care preferences.<sup>(397, 422)</sup>

An accountable homecare service ensures that their resources are used prudently and effectively to support an accessible and sustainable person-centred quality of care and support. The homecare providers must plan and organise their use of resources, including workforce and financial resources, taking into account the service users' needs, with a focus on early intervention and prevention. <sup>(305, 417)</sup>.

### **5.5.2 Leadership and governance**

In accountable homecare services, strong leadership is essential to ensure high quality person-centred care. The role of the manager and supervisor extend beyond personnel and financial management.<sup>(374)</sup> They are responsible for creating

relationships and motivation among homecare workers, strengthening the service's quality and culture, and encouraging and supporting teamwork. In addition, they need to inspire confidence, staff respect and facilitate open communication, which can result in a positive workplace environment, greater job satisfaction and high-quality of care.<sup>(423)</sup>

A 2020 study undertaken in Norway evaluated the link between leadership, job demands and resources, service user safety and work engagement in homecare settings. The authors reported that leadership characterised by motivating staff, and supporting and encouraging their development was positively associated with service user safety and staff work engagement.<sup>(423)</sup> These results may be explained by the fact that such leadership style gives staff an opportunity to develop and utilise their skills and competencies, which in turn is related to job satisfaction and quality of care. <sup>(374, 397, 423)</sup>

Research has shown that homecare managers and supervisors play a key role in developing and encouraging the organisational culture that supports service user safety, human rights, trust and integrity.<sup>(374, 397)</sup> A study from Norway with nurse managers of homecare services highlighted the importance of the internal culture and positive work environment. Most of the nurses reported applying an open leadership style that allows homecare workers to discuss problematic and ethical issues and reflect on their attitudes and values, for example, problems related to service user care. Some nurses cited values and principles that are part of the homecare service culture, such as encouraging service user independence, self-care and attempting to provide individual and holistic care to everyone. In addition, they also reported that as leaders, they feel responsible for supporting staff to maintain their enthusiasm and work engagement, especially when there is high work pressure due to staff shortages and heavy workloads. <sup>(374)</sup>

Managers and supervisors can also play an important role in supporting homecare worker's mental health.<sup>(379, 418)</sup> In a qualitative study undertaken in the UK, the homecare workers discussed work related stress and the lack of support received from their managers and supervisors. The study participants highlighted that, although they expect stressful situations to occur, the lack of support from management and supervisors made it more difficult to cope. In addition, they also reported a lack of support when there was a death of a service user who they cared for and with whom they had developed a close and friendly relationship. <sup>(379)</sup>

Other international studies also examined supervisors and colleagues' emotional support to carers in the context of service user death.<sup>(418)</sup> An American study found that homecare workers who received support found it helpful, mainly when this

support came from a supervisor. The participants also reported that having someone to talk to or to check-in with them was an example of the type of support they desired. <sup>(418)</sup> In addition, findings from another American study undertaken by the same authors suggested that homecare workers who worked for providers with a restrictive policy around service user death (that is, no follow-up contact with the deceased client's family is allowed) were more inclined to consider a job change, had lower job satisfaction and were unhappy with the supervision they received, compared to workers from providers without such a restrictive policy. <sup>(418)</sup>

### **5.5.3 Collaboration and integration between homecare, and health and social care services**

An accountable homecare service encourages open communication and information sharing to achieve integrated, coordinated and seamless care and support for service users. The homecare providers must demonstrate a sustained commitment and collaboration with a range of services including hospitals, primary care providers, consultants and nurses. In this context, homecare providers and other health and social care services should be open to developing structures and systems that improve the information management and sharing of service users' data within and between services. <sup>(419, 424-426)</sup> This information management refers to the collection, organisation and communication of the service users' needs, health status and care plans. <sup>(419)</sup> For example, an American study found that electronic patient-reported outcomes data can help evaluate the impact of early intervention on participation in home-based activities by children with developmental disabilities and delays. <sup>(427)</sup>

The evidence highlights that homecare and support services usually provide different types of care and support, from medical to social, that involve multidisciplinary teams and partners. <sup>(428-430)</sup> A Swedish study published in 2017 explored integrated care and how various professionals can best work together to deliver homecare and support services. The authors found that in situations where various health professionals care for older persons with multi-morbidities at home, close personal interactions between health and social care professionals, flexibility and improvisation were key to success. For example, despite team roles being specified, health and social care professionals must be prepared to complement and when appropriated, replace each other. <sup>(428)</sup> However, such variation of services and the transition of care from hospital to home may lead to inconsistent and inefficient information sharing between services. <sup>(429)</sup> This can result in unmet needs of service users, avoidable hospitalisation or re-hospitalisation, increased visits to hospital emergency departments, premature nursing home placement and consequently increase of healthcare costs. <sup>(426, 431)</sup> The evidence also highlights the positive impact of an integrated model of care, which provides a continuum of preventive and

curative services across primary, community, secondary and homecare settings, according to the needs of the service user over time.<sup>(432)</sup> There are three types of integrated care described in the literature:

- Linkage, which refers to the open communication and information sharing between services
- Coordination, which means having specific structures or a designated person to coordinate care across services
- Full integration, which refers to the re-organisation of all health, social, and supportive services under one financial source and organisation.

Research suggested that the integrated model of care can improve service users' health outcomes, enabling older adults, people with disabilities or those in need of complex care to remain at home.<sup>(425)</sup> In Canada, the Programme of Research to Integrate Services for the Maintenance of Autonomy (PRISMA) used a model which integrated all public, private and voluntary health and social services organisations involved in caring for older people. A randomised controlled trial compared the unmet needs of homecare service users living in communities with and without the PRISMA model of integrated care. This study found that the integrated model of care was effective in meeting long-term care needs in older adults, reduced the prevalence and incidence of functional decline, reduced their visits to the emergency department and increased service user satisfaction and empowerment.<sup>(425, 426)</sup>

Another study which evaluated the integrated care model in place for older people with complex needs in eight countries (Australia, Canada, the Netherlands, New Zealand, Sweden, the UK and the USA) found that the success of integrated care programmes relies on the care managers or coordinators who support patient-centred collaborative care. Care managers or coordinators work as a link between the older people, their family or informal caregivers, homecare providers, and health and social care services. For example, they were responsible for updating the homecare providers on changes in the service users' treatment or health status, they also ensure that service users were following the care plan, adhering to their medication and had access to the appropriate service.<sup>(433)</sup>

The research shows that homecare providers may experience issues with the quality of information shared with them by other health and social care services.<sup>(374, 397, 419, 432)</sup> A 2019 American study found that homecare providers often experienced fragmented information, as a result of obtaining information from different sources, for example, referral documents, hospital discharge paperwork, electronic health records, healthcare professionals and informal caregivers. According to the study

participants, in this process, some information was conflicting, especially around medication. For example, the homecare providers reported that the list of medication they received from the hospital was not the same list of medication they observed service users taking at home. In addition, homecare providers also reported experiencing missing information regarding the care plan implementation. For example, several times the discharge instructions from the hospital were not clear and the discharge summary was not available at the initial care visit. In this case, the service user and family caregiver became the first source of information about the care plan, which may lead to service-user safety issues and delay in care plan implementation. However, the same study found that those homecare providers who had one coordinator to manage the service-user transition of care (from hospital to home) had better information management systems in place and were more likely to receive the right level of information from the other health and social care services. <sup>(419)</sup>

This is supported by the findings from a Norwegian study with homecare nurses who reported several challenges faced during the process of transition of care after hospitalisation.<sup>(374)</sup> These challenges included cooperation, communication and clarification of responsibilities between the different organisations such as the hospital and the government commissioning unit responsible for purchasing the homecare service and developing the assessment care plan. For example, the nurses reported that service users with psychiatric conditions often need coordinated care with multidisciplinary teams from the psychiatric clinic in the hospital and homecare nurses that provide the general care. However, the participating homecare nurses outlined that in many cases they felt overlooked by the nurses from psychiatric clinics, as they were unwilling to share clinical information about the service users. This situation was described as frustrating and a limiting factor for good quality care and support.<sup>(374)</sup>

In addition, the same study also outlined communication issues between the commissioning unit and the homecare providers. The homecare nurses expressed concerns with the model in which the homecare provider has little or no input to the care planning. They cited that in many cases the assessment care plan was not shared with them in a timely manner. Therefore, they have to start the homecare visit before receiving the care plan and they felt that the care arrangements appear temporary or improvisatory. The participants also reported issues with the quality of the assessment of needs and care plan, which often can be incomplete or not meet the service users' needs, as a result, they had to do the assessment again.<sup>(374)</sup>

#### **5.5.4 Interaction between formal and informal caregivers**

The evidence shows that positive interaction between the formal and informal caregivers is vital to ensure a person-centred care service.<sup>(394, 434)</sup> This interaction includes information sharing, emotional support, and effective communication between the family, service user and provider. A 2018 systematic review of the literature found that the care partners (informal caregivers and or family carers) wanted to participate in the decision-making, particularly relating to how the care will be provided, when it will be provided and by whom. The authors highlighted that for the care partners, the high turnover of formal caregivers can be seen as a burden. In addition, care partners also wanted a trustworthy service that attends to their needs as carers and provides relief for care and support.<sup>(434)</sup> However, studies show that the relationship between formal and informal caregivers can be conflicting due to the lack of communication, providers' flexibility and structure for collaboration.<sup>(394)</sup> Therefore, there is a need to consider the informal caregiver as part of the care team. Also, the type of care provided by the formal and informal caregivers should complement each other to ensure a quality of life for the service users and their families.<sup>(384)</sup>

#### **5.5.5 Quality of care provided**

The homecare provider should focus not just on the delivery of their care service but also on the impact this care is having on quality of life of service users and their families.<sup>(435-437)</sup> A good quality homecare service is characterised by knowledgeable and skilled homecare workers, with effective communication skills, providing holistic and person-centred care. The evidence shows that from the service user's perspective, the quality of care is high when the providers are reliable, flexible and patient. Also, when the homecare workers have time to interact with them on a personal level, they can create a trust relationship.<sup>(397)</sup> In three studies, standardisation of work protocols and practices were noted as being important to quality control, from occupational therapy home assessment<sup>(438)</sup> to medication review upon transition to hospice care<sup>(439)</sup>, and in establishing workplace excellence for the homecare workforce as much as for hospital settings.<sup>(440)</sup>

The assessment of the quality of care provided is a vital step to ensure that service users' needs and expectations are being met and to target interventions to improve care <sup>(436)</sup>. The interRAI is a set of standardised instruments that was developed in US and is now used internationally, to provide reliable and person-centred assessment for individuals in community-based care settings. In the homecare setting, the interRAI Home Care (HC) Assessment collects information on physical, social, cognitive and mental health. The evidence from a systematic review highlights that at the provider level, this instrument offers an important opportunity to measure

quality improvement initiatives through the assessment of service users' functional status and quality of life, as quality indicators of the care and support of older people and people with disabilities.<sup>(435)</sup>

Researchers have developed the interRAI second-generation home quality care indicators (HCQI) based on two highly-used care assessment tools, the interRAI Community Health Assessment (CHA) and the interRAI Home Care (HC) Assessment. The new interRAI (HCQI) version added an advanced risk adjustment approach including measures of functional, clinical, social life, distress and service use. In addition, there was an inclusion of a set of 11 factors associated with the absence of functional decline and nine factors related to functional improvement. Based on these indicators, two summary scales, made up of 20 measures were developed: the 'Independence Quality Scale' which refers to low rates of service user functional decline (for example, for falls, injury, hospital emergency departments visits, mood decline, bladder decline, and uncontrolled pain), and the 'Clinical Balance Quality Scale' characterised by high rates of service user functional improvement (for example, bladder improvement, mood improvement, pain improvement, caregiver not distressed, and not alone and distressed). These two scales can provide a view of the overall effectiveness of homecare performance and therefore, identify areas in need of improvement.<sup>(441)</sup>

A 2015 European study undertaken in six countries (Czech Republic, Denmark, Finland, Germany, Italy and the Netherlands) assessed the quality of homecare services using the interRAI (HCQI). The authors found that functional decline measures indicated a lower quality of care provision and a need for improvement in the service. In this study, a high proportion of service users showed a decline in IADL function. When they examined clinical indicators, a decline in mood was the most prevalent, while being alone and distressed were the most prevalent social indicators to decline. Therefore, the authors concluded that service users' functional declines were the areas most needed for interventions and improvement in these countries. The use of the interRAI (HCQI) at the provider level can help improve care planning. At the regional and national level, it can help in the development of initiatives aiming to improve the homecare providers' accountability in care performance and service user outcome.<sup>(301)</sup>

A 2013 pilot study undertaken in Ireland evaluated the usability, practicality and acceptance of the interRAI in the Irish healthcare context. The study participants included 45 healthcare professionals, 68 older persons and 15 informal caregivers. Most health professionals found that the interRAI tools have a clinical value and are easy to use. In the open-ended questions, the healthcare professionals reported that the interRAI is comprehensive in identifying clients' health and social care needs. In addition, they cited that the system supports the development of care planning and

is user friendly. The negative comments included the difficulty in entering clients' medication and disease diagnostics into the system (the entire International Classification of Diseases (ICD) was loaded into the software system, causing delays in accessing appropriate codes for clients' diagnoses). The healthcare professionals also cited the time to complete the assessment, terminology and coding variance of the interRAI practice standard from the Irish practice standards, and IT issues as barriers to developing a person-centred care assessment and plan. Overall the authors concluded that the interRAI demonstrated positive feedback from the Irish healthcare professionals. In addition, the authors highlight that education and training sessions can target areas of concern. <sup>(442)</sup>

Another study conducted in Germany also evaluated the quality of homecare services using a different care assessment tool, the Barthel Index. In this study, the authors compared the homecare users' Barthel Index score with the level of care received. The authors found that a quarter of service users receiving level 1 care (90 minutes a day of minimum support in two areas of basic care - nutrition, mobility, hygiene and household assistance) actually required more care based on their Barthel Index score. Thus, they were receiving an undersupply in the level of care. Conversely, a quarter of service users who received level 2 care (three hours daily of basic care – nutrition, mobility and hygiene and household assistance) were getting more care than they needed. The research highlights that to improve the quality of care, there is a need for continuous assessment to detect changes in service users' needs. <sup>(422)</sup>

### **5.5.6 Sustainability**

Sustainability in the homecare sector is related to resource management, including human and financial resources, to ensure the range of services they provide are delivered in a safe, consistent and person-centred way. In terms of workforce resources, homecare workers play a key role in maintaining and improving service users' quality of life. Any shortage in homecare staff can not only limit the access to the service but also have a negative impact on the person-centred quality of care. <sup>(379, 416, 417, 443)</sup> The evidence shows a high turnover of homecare workers due to low job satisfaction and working conditions. <sup>(379, 416, 417)</sup> A 2021 literature review conducted in Canada reported that the employment conditions of homecare workers, such as lack of professional regulation, low wages, irregular work scheduling, part-time positions and lack of health benefits, led to workers feeling undervalued. <sup>(444)</sup> In addition, another Canadian study also identified work environment characteristics linked with low job satisfaction of homecare workers. For example, work schedule, including the number and distribution of work hours, was cited as a source of job dissatisfaction, due to unpredictable and erratic work hours with long unpaid gaps in the workday and long travel between clients. <sup>(416)</sup> Supporting this finding, a study

from the UK also reported the irregular work schedule as a stressor for homecare workers, due to the negative impact on their work-life balance. Homecare workers often cited difficulties in maintaining family and social life outside their job, due to unpredictable work hours. To overcome this issue, some participants discussed that their organisation allowed them to be flexible in their work hours.<sup>(379)</sup> Indeed, another study undertaken in Canada with homecare nurses found that flexibility in work schedules was an important reason to stay working in the homecare sector. The authors highlighted that homecare providers should implement work schedules and models of care that facilitate flexibility of care to improve workforce retention.<sup>(445)</sup>

A 2018 study undertaken in the UK reported that 60% of local homecare staff work zero-hour contracts. The homecare workers reported that this type of contract is a further stressor in their work environment due to financial uncertainty, as they do not have set hours of work, which led to difficulties in planning personal lives and paying bills. <sup>(379)</sup> A literature review from Canada also found that compensation issues such as low salaries and salary disparities within and between providers, limited benefits, unpaid breaks and unpaid travel time between service users' homes, are disincentives for entering or remaining in the job.<sup>(417)</sup> In addition, workloads characterised by too much or too little work, with high levels of stress, safety concerns, job insecurity (due to the lack of professional regulation) and feeling undervalued can also impact homecare workers' mental health and job satisfaction and is a significant predictor of work turnover. According to the authors, the homecare providers can take initiatives to address these issues and improve the work environment. Such initiatives may include:

- attractive salaries and benefits
- promoting manageable work-life balance, with flexibility, a positive work environment and support staff for time off
- ongoing training and development
- implementing predictable scheduling and full-time hours
- managers, supervisors and peers open communication and support, including supporting the relationship between workers and service users by providing consistent and continuous work assignments and participation in care planning
- opportunities for career progression.<sup>(417)</sup>

A 2017 literature review identified characteristics of effective homecare nurses in order to aid interviewing and retaining staff. The identified characteristics included a high level of hands-on skills, training and knowledge in community health, advanced organisation and documentation skills ability.<sup>(387)</sup> An American study of a mentorship

programme for newly-hired homecare nurses further highlighted the role of training and mentorship in retaining staff.<sup>(446)</sup> To reduce the risk of burnout and staff turnover, another study in Sweden pointed to the importance of competence development and the desire of nurses to have confidence in their skills and abilities.<sup>(447)</sup>

International research has highlighted that both the growing need for homecare and support services and staff shortages have caused homecare providers to look at more efficient and effective use of the homecare staffing resource.<sup>(397)</sup> A 2015 study evaluated the impact of up-skilling homecare workers by task shifting, which consisted in task delegation by a nurse, physiotherapist or occupational therapist to home support workers. This task shifting included simple wound care, exercises, medication management, catheterisation, colostomy care, compression stockings, gastrostomy-tube feeding and continence care. Some home support workers reported that task shifting improved consistency and continuity of care, as they visit service users more frequently and spend more time with them. Also, they reported being less rushed with care activities which helped ensure clients' comfort, more person-centred care and reduced the number of different healthcare professionals visiting the service user. Conversely, time constraints to complete all care tasks were perceived as a negative impact by other home support workers, as they reported concerns with the quality of care provided. In addition, the homecare nurse managers and healthcare professionals also discussed further negative impacts of the task-shifting such as insufficient training, inadequate delegation of tasks, lack of supervision, and scheduling.<sup>(397)</sup>

With regard to the financial resources, an accountable and sustainable homecare service must also be cost-effective. A 2020 Irish study highlights that improvements in homecare services are likely to come with a substantial financial cost that would require public support, such as additional taxes or charges. Thus, this study evaluated the willingness of the participants (551 individuals, aged over 18 years, the majority were female, married or living as married, and with a degree or postgraduate diploma) to support changes in the health and social care budget to ensure person-centred care arrangements for people with dementia. These changes include personalised communication, high flexibility and an adequate supply of formal care hours. Findings from this study indicated that the participants were willing to pay €109.11 per year in additional taxation for a homecare system that provides personalised communication compared to standardised communication, and €117.28 for a system that offers high flexibility compared to low flexibility and €116.65 for 20 hours of homecare per week. In addition, the participants accepted the means tested co-payment charges, however, they were against the compulsory co-payment.<sup>(448)</sup> A population-based study undertaken in North Wales in 2013

developed an economic model to estimate the additional cost of offering end-of-life care at home, based on children's and parents preferences. The authors created an end-of-life scenario at home: one week of end-of-life care at home showed an additional cost of £14,000 per child per week (2010/11 prices). This scenario included children's community nurses trained in palliative care, technical support for medical equipment, travel expenses for staff and the provision of psychological support for families <sup>(449)</sup>.

A 2017 systematic review of literature appraised intervention studies aiming to explore ways to improve homecare services through the implementation of cost-effective, multidisciplinary, intensive and short-term programmes that help service users to regain or retain their confidence and re-learn the skills necessary for daily living to maximise independence. The intervention studies refer to the implementation of Re-ablement, Reactivation, Rehabilitation and Restorative (4R) programmes in the homecare setting:

- Re-ablement and reactivation aim to help people to return or stay in their own home as long as possible by supporting service users to regain confidence and skills necessary for daily living
- Rehabilitation and restorative care focus on regaining or retaining service users' physical function, following debilitating effects of illness or injury, achieving the best level of functional ability.

These care programmes were delivered by an interdisciplinary team such as rehabilitation aides, physical and occupational therapists, home support workers and nurses. In addition, most interventions were led by home support workers supervised by physical and occupational therapists, and nurses. The 4R intervention studies were focused on service users' functional capabilities, including the ability to complete activities of daily living (ADL) and involved rehabilitative exercises, home modifications, task redesign, education regarding self-care, falls prevention and nutrition. The systematic review of literature found that nine of the 15 studies reported an overall decrease in the use of homecare services, with a shorter length of time receiving the homecare, fewer homecare hours and lower homecare costs over time. Seven of the 15 studies found improvements in participant's functional abilities such as an increase in ADL and IADL scores, improved ability in the kitchen in terms of meal preparation and the execution of domestic tasks, and better self-care. However, the authors outlined that although the evidence from the intervention studies found positive outcomes on service users' functional ability, further research on the structure underpinning such programmes must be considered.<sup>(415)</sup>

### 5.5.7 Conclusion

An accountable homecare service ensures that service users receive high quality care that is safe, consistent, coordinated and focused on supporting people to live at home. Accountable organisations have a clear vision for their work, support their staff to deliver this vision, are focused on the service-user and work well with other relevant services, as well as family members or unpaid carers.

The key insights for the development of standards for homecare and support services are:

- A client's involvement is at the core of a successful homecare service. An accountable provider of homecare services involves users in decision making, supports service user autonomy and dignity, and facilitates users and their families or carers to exert control over their own care and support
- For service users, an effective, high-quality and therefore accountable homecare service ensures consistency and continuity of care and support to individual service users. This requires accountable providers to plan and organise resources, including their workforce and financial resources, to take account of the needs of service users. Accountable providers will also implement work schedules and models of care that facilitate flexibility of care delivery and also improve workforce retention
- Homecare and support services are delivered by individual workers to individual service users. An accountable provider will seek to develop a culture of delivery of high-quality care, through motivating, supporting and developing their workforce. This includes ensuring that staff have the necessary knowledge and skills to deliver the care and support required by an individual service user
- Homecare and support services do not operate in isolation. Accountable providers seek to achieve integrated, co-ordinated and seamless care and support by communicating and collaborating effectively with a range of other services. These include hospitals, primary care providers and other health and social care services, as well as the service user and their families and carers
- Effective collaboration requires clear and timely communication of key information, both within the organisation and with external partners in the delivery of care. Accountable organisations should put in place information management systems in line with a clear governance framework which are reliable, secure and shared in a timely and appropriate manner.

### 5.6 Other findings from academic and grey literature

This section outlines findings from targeted searching conducted to look at the areas of implementation, economics of homecare, and telehealth. In-depth systematic literature searching was not conducted for these areas, as this was outside of the

scope of this evidence review which was conducted to inform the development of the standards. Rather, targeted searching was conducted to present a high level overview of these areas. This section outlines findings from academic and grey literature that is not contained within the four principles of the Standards Development Framework. These findings are presented in the context of homecare and support services under the following headings:

- Implementation
- Economics of homecare
- Telehealth.

### 5.6.1 Implementation

In 2018, the Standards Team in HIQA conducted a review examining how standard-setting bodies internationally develop standards and guidance. The review identified 13 standard-setting bodies in nine jurisdictions with a similar remit to HIQA in developing standards and guidance.<sup>(303)</sup> Key findings included that standard-setting bodies are placing a focus on developing support materials and guidance related to national standards for health and social care services.<sup>(303)</sup> These support materials and guidance are implementation strategies that aim to help, promote and enhance the implementation of standards across health and social care services. Examples of implementation strategies used by standard-setting bodies internationally include support tools such as infographics, posters, easy-to-read booklets, leaflets and frequently asked questions (FAQs).<sup>(303)</sup> Based on this learning, the Standards Team at HIQA has set a strategic objective to support implementation of standards in order to drive improvements and consistent interpretation within health and social care services. This objective encompasses key priorities that include adopting an implementation science approach across the standards-setting function, reflecting the scientific methodologies in our processes and developing methods for the development of support tools for standards on an ongoing basis.<sup>(450)</sup>

Adopting an implementation science approach will seek to learn and understand how standards work in 'real world' settings. In addition, an application of implementation theoretical underpinnings will facilitate an understanding and explanation of implementation. As such, theoretical approaches will be applied to:

1. Describe and guide the process of translating standards into practice.
2. Explain and facilitate an understanding of what influences implementation outcomes.
3. Evaluate the implementation of standards in practice.

There is an array of published implementation theories, models and frameworks with the *Exploration, Preparation, Implementation, Sustainment (EPIS) framework*<sup>(451)</sup>,

*Consolidated Framework for Implementation Research*<sup>(452)</sup>, *Normalisation Process Theory*<sup>(453)</sup> and *The Behaviour Change Wheel*<sup>(454)</sup> among those used in published research.

The selection and design of implementation strategies is central to implementation.<sup>(455)</sup> Tailoring implementation strategies enhances uptake of an intervention such as standards, whereby adaptations are made to the implementation strategies so they are suitable for the intended users and services. In addition, the tailoring process promotes embedding evidence in everyday practices. This process involves identifying determinants that influence implementation of standards, matching strategies to the determinants and then applying strategies in practice and finally assessing their effectiveness through implementation outcomes.<sup>(456)</sup> Determinants are factors that influence the implementation process; those that typically influence implementation of standards are set out in Table 5.1. Determinants can act as factors that enable (facilitators) or hinder (barriers) implementation. They include:

- Characteristics of the standards.
- Stakeholders involved in implementing the standards, for example frontline staff, service managers, executive decision-makers and policy-makers.
- The service users upon which the standards are intended to have impact on.
- The setting where implementation occurs.
- Strategies to facilitate implementation, for example support tools.

**Table 5.1: Determinants of implementation**

Implementation Object	Implementers	Target	Context	Strategies to facilitate implementation
Health and social care Standard	Health and social care stakeholders	Person using the service	Health and social care setting	Support tools and guidance

**Source:** Various. Determinants of implementation.<sup>(453, 457)</sup>

It is important to note that implementation is not a linear process, which can be attributed to the complexity of health systems.<sup>(453)</sup> As such, there are many contextual factors that influence implementation that tend to be dynamic in nature. Context has been recognised as a complex term with variable interpretations but

usually represents organisational cultures and climates, financial resources, social relations and support.<sup>(457)</sup> A 2016 study highlighted that factors that are barriers to implementation in one service or setting may facilitate implementation in another service or setting.<sup>(453)</sup> There is a need to understand how and why this happens, in order to understand how implementation can scale up and spread. Scale-up refers to increasing implementation over time and then spreading across settings and services.

There is a scarcity of research pertaining to tailoring implementation strategies. Moreover, there is a lack of research specific to implementing standards for homecare and support. Nonetheless, Ireland can learn from experiences from international standard-setting bodies. For example, the National Institute for Health and Care Excellence (NICE) in the United Kingdom has developed and published guidelines on *Home care: delivering personal care and practical support to older people living in their own homes* in 2015.<sup>(154)</sup> Alongside key stakeholders, NICE identified areas that may pose challenges to the implementation of the guidelines and subsequently suggested changes to overcome these challenges. For example, perceived challenges included providing person-centred care to deliver better quality of life for the person using services and greater job satisfaction for the workforce.<sup>(154)</sup> To overcome these challenges, NICE developed a suite of tools to help services adopt person-centred resources, entitled *Tools to help you put the guidance into practice* and are categorised according to 'education,' 'audit and service improvement' and 'shared learning' and include webinars, podcast, case studies and shared learning.<sup>(154)</sup>

Similarly, the Aged Care Quality and Safety Commission in Australia has developed and published *Guidance and resources for providers to support the Aged Care Quality Standards*, using best available evidence and stakeholder engagement. These support materials aim to assist aged care services including homecare and support services to implement and comply with their Quality Standards. They encompass case studies describing good practices and learning from experiences, information on expected performances and assessments of compliance with Standards. The materials include posters, factsheets, webinars and videos.<sup>(289)</sup>

### **5.6.2 Economics of Homecare**

This section provides an overview of cost-related measures in homecare and support services. While a review of cost effectiveness was outside the scope of this evidence review, which is focused on evidence to inform the development of national standards, this section highlights evidence from reviews on national and international financing in homecare.

According to the Economic and Social Research Institute (ESRI), Ireland has one of the highest levels of unmet homecare and support needs in Europe.<sup>(4)</sup> The ESRI report that, in Denmark, 54% of families receive formal homecare and support for someone in the household who needs help. In Ireland, this figure is just 24%. Home support services in Ireland are provided by a combination of the HSE, voluntary organisations and for-profit organisations. The majority of home support is provided by for-profit organisations in Ireland. In 2019, approximately 33% of total home support was provided by HSE staff (8.2 million hours), 9% was provided by the voluntary sector (2.1 million hours), and 58% was provided by for-profit organisations (14.4 million hours).

In general, funding for homecare and support has been described as being 'fragmented' and this is reflected in variation of price-setting mechanisms across different jurisdictions: prices are often determined by negotiations between the purchaser and the provider and, while in theory, this has the potential to promote affordability of services, this result may be offset due to the lack of availability of resources such as formal carers.<sup>(13)</sup>

According to multiple reports, financing of homecare and support should be linked with need, through transparent mechanisms for assessment.<sup>(4, 13-15)</sup> One particular report commissioned by the OECD on the financing of long-term care, which included homecare, noted that patterns of expenditure in the homecare sector are largely based on factors relating to supply, rather than the demand for homecare: for example, the availability of formal carers. The primary cost in homecare is paying for trained carers, however strictly controlling costs in formal homecare can result in reduced pay for trained carers, reduced hours of care, or the employment of underqualified carers who will work for a lower hourly rate. According to the ESRI, potential risks related to personal budget constraints may include a lack of implementation of regulated standards and a lowering of the quality of care. Similarly, according to the OECD, a system where homecare is influenced largely by stringent cost control may lead to unmet needs, due to the narrowing of eligibility criteria in order to manage demand.<sup>(14)</sup>

An ESRI report entitled 'Demand for the Statutory Home Support Scheme' is the first of three research projects funded by the Department of Health to inform the cost implications of the development of a statutory home support scheme in Ireland.<sup>(4)</sup> The report estimates the potential demand for home support if a statutory scheme were to be introduced under various policy scenarios including:

- increasing home support to all older people waiting for a support package or additional hours

- reducing by half the number of people who exit the home support scheme and enter long-term residential care
- increased demand for professional support from people who require help with their Activities of Daily Living (ADL).

According to this report, an estimated 24.7 million home support hours were provided in 2019 to over 65,000 people aged 65 years and older. A quarter of these hours were privately purchased. Compared to the level of home support provided in 2019, increasing home support to all older people waiting for a support package or additional hours would require an extra 3.5 million hours. Halving the number of home support recipients who enter long-term residential care, by providing them with adequate intensive home support packages would require an extra 4.2 million hours. Up to 8 million additional hours of home support may be required to meet the increased demand from people with Activities of Daily Living (ADL) difficulties, who may have previously relied on unpaid and family care. A proportionate increase in the carer workforce would be required to meet increased demand.<sup>(4)</sup>

Intensive homecare packages (IHCP) for people requiring more care hours or more complex care at home incur a larger cost. The costs of standard IHCPs varies in each case depending on need and availability of services. For example, the average weekly cost of a standard IHCP at the end of December 2017 was €1,024, but this ranged from €399 to €3,500, with a median cost of €936.<sup>(13)</sup>

A report commissioned by the OECD recommends that countries have a dedicated funding stream for homecare and support services. Currently, some countries ring-fence funds for homecare and support, while others use National Insurance schemes to pay for homecare and support for its citizens. While ring-fencing of funds for homecare and support prevents the use of this funding for other means and promotes transparency, according to the OECD report, it also has the potential to reduce co-ordination between health and social care agencies.<sup>(14)</sup>

Lastly, according to multiple reports, the success of any statutory homecare and support scheme can be determined by its ability to meet demand for services. Multiple national and international reports predict significant increase in the demand for home support in the coming years, largely due to an ageing population.<sup>(458)</sup> These reports recommend investment in strategies for early intervention of homecare and support services to reduce costs relating to hospital admissions and the need for longer-term, and more intensive care packages to allow for more complex care to be delivered in the home setting.

### 5.6.3 Telehealth

The increased demand for homecare and support services call for health reform and cost-saving mechanisms to promote independence and provide complex care for people who need support to live at home.<sup>(17)</sup> In homecare and support services, telehealth may facilitate everyday tasks, improve service users' safety, and decrease the informal caregiver burden. Telehealth may offer an opportunity to help address issues and challenges in the homecare and support sector, such as shortage of skilled staff and increased demand for long-term care.

According to the World Health Organization (WHO), telehealth and telemedicine are synonymous and they are broadly defined as "the delivery of health care services, where distance is a critical factor, by all health care professionals using information and communication technologies for the exchange of valid information for diagnosis, treatment and prevention of disease and injuries, research and evaluation, and for the continuing education of health care providers, all in the interests of advancing the health of individuals and their communities".<sup>(18)</sup>

Telehealth includes interventions that use information communication technologies (ICT), telemonitoring (for example, telemetry devices to capture a specific vital sign, such as blood pressure, glucose, weight or heart rhythm), sensors, electronic health records, assistive devices, e-learning, educational technology, decision support, tracking (to locate people or objects such as GPS trackers) and personal medical records and so on.<sup>(459)</sup> Implementing telehealth in homecare and support services can be challenging and requires a change to service organisation. For the providers and healthcare professionals, the implementation of telehealth can be perceived as an additional work burden in an already high-pressured work environment.<sup>(302)</sup> In addition, adjustments of current practice, including changes to staff attitudes and the culture of homecare and support services, knowledge and skills, are also needed. In this context, homecare and support worker training are fundamental to safe and effective telehealth practice.<sup>(460)</sup>

In the homecare setting, the evidence regarding the effectiveness of telehealth is still unclear but the impact in terms of quality of life, hospital admissions and cost-benefit has been evaluated in several studies.<sup>(19, 461)</sup> A systematic review and meta-analysis published in 2020 compared the effect of telehealth versus usual homecare, over a period of 12 months. The study found a lack of association between telehealth and improved quality of life, mental health and physical health outcomes. The results regarding cost-benefit were inconclusive. From the service-users' perspective, telehealth was cited as "peace of mind", facilitating access to healthcare professionals and improving ownership of their care. However, the negative side of

telehealth was also noted and included less personal contact, loneliness and invasiveness caused by monitoring equipment.<sup>(462)</sup>

In terms of complex care technologies, a 2018 systematic review of the literature found that using medical technology in the home setting can have both positive and negative psychosocial impacts on service users and their families. On the positive side, service users can gain more independence, improve their overall health and have a better quality of life. Conversely, for some service users, the dependency on others for daily activity, socially restricted life and perceived stigmatisation were cited as barriers to medical technology usage. The authors also highlighted the need for adequate training and education programmes for service users, their families, homecare workers, homecare providers and healthcare professionals, to ensure service users' safety and wellbeing.<sup>(463)</sup>

In Ireland, telehealth has yet to be consistently employed in health and social care services, including homecare and support services. An Irish pilot study looked at the viability of telehealth service in homecare, including clinical monitoring and self-management technologies. The pilot study found that the vast majority of service-users who engaged with the telehealth devices reported a positive impact on monitoring and managing their chronic disease and improving self-confidence in this regard. However, the extent to which telehealth could assist service users to remain in their home for longer were unclear.<sup>(464)</sup>

Despite the shortage of studies documenting the cost-effectiveness and health benefit of telehealth in homecare, its role tends to grow as technology develops and the demand for homecare increases, with population preference to age or be cared for in their homes.<sup>(459)</sup> However, care must be taken to ensure that telehealth is implemented intelligently to maximise health services and quality of care.<sup>(18)</sup> In the homecare and support sector, telehealth could provide an additional support to help address service-users' needs and enable them to manage their health and overall wellbeing. In addition, adequate preparation and training of homecare and support providers, workers, service users and their families are essential to implement a safe, effective and efficient telehealth service.<sup>(460)</sup>

As outlined, telehealth is used by homecare and support services for a variety of reasons. However, due to the myriad of different technologies and the volume of evidence available, a detailed, in-depth review of its use, effectiveness and cost effectiveness were outside the scope of this evidence review. Nevertheless, it is recognised that the current use of telehealth, along with the potential increased use and demand in the future, will impact on the structure and delivery of homecare services in the future.<sup>(19)</sup> As recommended by HIQA in 2021, there is a need to

undertake an assessment of the effectiveness and cost-effectiveness of health technologies in homecare and support in the Irish context.

## **5.7 Summary of evidence synthesis**

To summarise, the findings from the academic and grey literature provide evidence for a person-centred approach to homecare and support services, where people and their families are involved in decisions around their homecare and support, and organisations and individuals work towards achieving the best outcomes for the person using services.

The principle of 'a human rights-based approach' revealed the importance of non-discrimination in care and support, where people, and their families, as appropriate have equitable access to homecare, home support and respite services. The findings under this principle also revealed the importance of autonomy and choice, where people are informed about their care and support options. This also involves communicating in an accessible way with respect to the needs of the individual using services, and ensuring that people's individual needs and preferences are incorporated into the care-planning process. It is important also that people working in homecare and support services have their human rights respected, and that they do not experience discrimination.

The principle 'safety and wellbeing' revealed the challenges that people using homecare and support services may experience, particularly challenges to their quality of life and their mental and physical wellbeing. While the evidence revealed the benefits of caring for people in their own homes for as long as possible, it was also highlighted that steps should be taken to prevent the person's home from becoming overly clinical or medicalised. According to the evidence, the quality of life of people using services can be maximised by ensuring their participation in their community and their social connectedness, where this is possible. The importance of safeguarding service users against all forms of abuse was also highlighted under this principle. The safety of the health and social care professional also emerged under the principle, and it was highlighted that organisations should take steps to recognise and prevent stress and burnout in homecare workers, and also safeguard homecare workers against abuse.

Evidence synthesised under the principle 'responsiveness' revealed commonly reported issues around workforce planning and terms of employment from the point-of-view of homecare workers and health and social care professionals working in people's homes. It emerged that homecare workers often experience constraints relating to duration and timing of visits, particularly where people are allocated slots of only 30 minutes or less. Furthermore, access to training can be a challenge, and the evidence revealed the importance of condition-specific training and education to

enhance awareness of the individual's needs, particularly in people with complex care needs or dementia. Furthermore, the importance of collaboration and integration of care was highlighted: the evidence revealed the importance of working together with family carers to bring about the best outcomes for the people using services, and also the importance of working together with professionals from other disciplines and inter-agency collaboration.

The principle of 'accountability' highlighted the importance of robust leadership and governance arrangements in organisations providing homecare and support services. Sustainability emerged as a major theme under this principle, and this includes sustainability of workforce planning and retention of staff, promoted by access to training, models of care, and flexible work schedules. According to the evidence, in an accountable service, prompt, appropriate information-sharing is key in promoting transparency and should be enabled by a strong and clear governance framework, and open communication between organisations and with people and families.

The cost-effectiveness of homecare and support services was highlighted, and it was noted that the evidence reveals benefits in reducing costs associated with hospital admissions and long-term stays in residential centres. Furthermore, a targeted analysis of telehealth and digital interventions in homecare and support services revealed potential benefits in terms of early intervention and promoting accessibility of care at home. Lastly, the evidence explored the importance of targeted implementation strategies to optimise sustainable implementation of standards and how this learning can be applied to the National Standards for Homecare and Support Services.

## **6. Summary, conclusion and next steps**

Strong and effective governance arrangements are required at national, regional and local service-delivery level, to ensure that people using homecare and support services receive consistent coordinated care. Systems and structures to support collaborative working and communication between homecare services and other health and social care services are needed, to ensure that people get the integrated care and support they need and that the information required to drive quality and safety is available when and where it is required. Service provision should be based on a standardised assessment of needs.

The learning from the COVID-19 pandemic and best practice internationally will inform the development of evidence-based person-centred standards for homecare and support services in Ireland, which focus on the safety, dignity and wellbeing of the person using the service, enabling them to live in their own homes for as long as

possible. Regulations and standards should apply to all homecare and home support services, without restrictions, such as age.

While the challenges in relation to the design, delivery and oversight of homecare and support services are common across all countries examined and in the available evidence, Ireland is uniquely well placed, not only to learn from experience elsewhere in the world, but also to develop standards for homecare and support services that reflect the national policy and priorities, and that are person-centred, outcome-focused and robust enough to support service users in a complex and evolving health and social care environment.

The findings from this evidence review, along with extensive stakeholder engagement and consultation, will inform the development of Draft National Standards for Homecare and Support Services. These standards will promote quality improvement within services by setting out what high-quality and safe homecare and support services for people should look like, and will support and assist service providers to ensure best practice and a quality person-centred service. Following approval by the Board of HIQA, the standards will be submitted to the Minister for Health for approval. The approved standards will be made publicly available on the HIQA website. These standards should be implemented in parallel with other statutory and regulatory frameworks that services and staff are required to follow.

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## Appendix

### International organisations contacted during the development of the evidence review

<b>Organisation</b>	<b>Jurisdiction</b>
Care Inspectorate	Scotland
Care Inspectorate Wales	Wales
Department of Health	Northern Ireland
Regulation and Quality Improvement Authority (RQIA)	Northern Ireland
Care Quality Commission (CQC)	England
Department of Social Services (DSS)	Australia
NDIS Quality and Safety Commission	Australia
Ministry of Health, Health System Improvement and Innovation	New Zealand
Health and Youth Care Inspectorate Ministry of Health, Welfare and Sport	The Netherlands

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