Health Information and Quality Authority

An tÚdarás Um Fhaisnéis agus Cáilíocht Sláinte

Health Information and Standards

Evidence review – Residential services for children and adults with disabilities

September 2025

Safer Better Care

About the Health Information and Quality Authority

The Health Information and Quality Authority (HIQA) is an independent statutory body 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.

Reporting to the Minister for Health and engaging with relevant government Ministers and departments, 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 of Social Services 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 permanent international protection accommodation service centres, health services and children's social services against the national standards. Where necessary, HIQA investigates serious concerns about the health and welfare of people who use health services and children's social 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 and social care services, with the Department of Health and the HSE.

Visit www.hiqa.ie for more information.

Acknowledgements

This report was led by staff in HIQA's Health Information and Standards Directorate.

Name	Role
Cathy Duggan	Project Lead
Caroline Walsh	Research Officer
Catherine Waldron	Research Officer

The following individuals from HIQA's Health Information and Standards Directorate also contributed to the management, writing and dissemination of this report: Rachel Flynn, Niamh O'Rourke, Valerie Ferguson, Deirdre Connolly, Fiona Geaney, and Elena Vaughan.

Conflicts of Interest

None reported.

Table of contents

Tables and Figures

Executive Summary

Introduction

In 2013, HIQA published the ministerially approved *National Standards for Residential Services for Children and Adults with Disabilities* that set out what a good quality, safe residential service for people with disabilities should be.(1)

To ascertain what has changed in the sector since the standards were published in 2013 and to inform discussions on next steps, HIQA undertook an evidence review of relevant national and international documents, and peer-reviewed literature. The aim of this evidence review is to identify important areas for inclusion in any updated standards. In line with HIQA's process for updating existing standards, this review comprises three main elements:

- an overview of the regulation of residential services for children and adults with disabilities in Ireland
- a review of international standards and related documents for residential services for children and adults with disabilities
- scoping review of peer-reviewed literature to identify the characteristics of person-centred care in residential services for children and adults with disabilities.

Overview of the regulation of residential services for children and adults with disabilities in Ireland

In 2013, HIQA commenced the regulation of residential services for people with disabilities in Ireland. Under the Health Act 2007, the Chief Inspector of Social Services within HIQA is legally responsible for the monitoring, inspection and registration of designated centres for children and adults with disabilities.(2) HIQA publishes reports of inspections carried out in specific services and publishes overview reports to summarise the key findings from services across Ireland.

In 2024, HIQA published an overview report on *10 Years of Regulating Designated Centres for People with Disabilities*.(3) This report sets out the impact of regulation in this sector from 2013 to 2023, detailing important findings and learnings, as well as reflecting on current and future challenges for the sector.(2) Key findings from this report, along with other relevant sources such as legislation, were extracted, and areas of significant change since 2013 were identified and described in this evidence review.

The national evidence indicates that there have been several developments in the sector since the standards were first published, and these developments should be considered in any update to the standards:

- Ireland ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCPRD) in 2018, committing to promote, protect and ensure equal enjoyment of all human rights and fundamental freedoms for people with disabilities.(4)
- The Assisted Decision-Making (Capacity) Act 2015 (ADMA) which commenced in 2023, emphasises maximising a person's autonomy, promoting a human rights-based approach that prioritises the person's will and preferences.(5)
- There is an increased focus on understanding and communicating the voice and experience of the person living in a residential service, to ensure their human rights are upheld and their choices and preferences are respected.(3)
- Nationally, it was found that some services still have practices in place that infringe on residents' rights to freedom of movement, access to supported decision-making, and choice and control in their daily lives. Therefore, further improvements are needed to fully transition to a human-rights based approach to care and support.
- The ongoing process of decongregation*, transitioning from large, congregated settings to smaller centres in the community, is improving resident outcomes and quality of life.(3,6)
- Regulations have placed stricter controls on the use of restrictive practices† in this sector, resulting in changes in both practice and culture among staff working in designated centres.(3)
- There is heightened focus on good safeguarding practices, which can reduce the likelihood of harm and abuse for residents.(3)
- There has been a shift towards a social model of care, away from a task-oriented way of working. This has contributed to a more person-centred approach, informed by human rights principles.(3)
- There is an increased focus on effective governance arrangements that improve levels of compliance, quality of life for the residents, lines of communication, and the providers' ability to respond to crises.(3)

---

* Decongregation involves moving people with disabilities from congregated settings, places where 10 or more people live together or are based in a campus-style setting, to homes in the community.

† Restrictive practices are defined in the Health Act regulations as the 'intentional restriction of a person's voluntary movement or behaviour'.

There is a need for further reform in policy and legislation for Ireland, including the need for adult safeguarding legislation and reform of the Health Act 2007 and associated regulations to reflect a more human rights-based approach.(3)

Review of international standards and related documents for residential services for children and adults with disabilities

A desktop search of 37 countries and a search of three academic and grey literature databases was conducted to identify and describe relevant standards in this area and to highlight areas where lessons can be learned for Ireland: 17 documents from nine countries‡ were identified for inclusion in the review of international standards and related documents.

Key areas identified that should be considered in any update of the *National Standards for Residential Services for Children and Adults with Disabilities,* include:

A human rights-based approach:

- There is a consensus that people with disabilities have the same human rights as everyone else.(7-15)
- People with disabilities have the right to feel safe and secure in all aspects of their lives and to receive the right care at the right time.(12,13,16)

Safety and wellbeing:

- There is a focus on the provision of safe care, with zero tolerance of abuse, harm and neglect.(9,10,16,17)
- There is a need for services to be tailored to people's needs over the course of their life, with a focus on wellbeing.(18)
- Decongregation and a move to supported, small residential care settings in the community was a target for most countries.(11,19)
- People with disabilities, and children specifically, need support in transitioning within or between services.(12,13,18)
- More timely assessments of need are required.(10,18,20,21)

Responsiveness:

- Staff have an important role in ensuring they apply the characteristics of person-centred care in their work, this includes placing the person at the centre of everything, considering their personal needs and preferences,

---

‡The 17 documents included standards, guidance, strategies and policies, from Australia, Canada, England, New Zealand, Northern Ireland, Scotland, Slovenia, Sweden and Wales, relevant to residential services for children and adults with disabilities.

providing appropriate support and fostering partnerships with their friends and family, as appropriate.
- Staff need to have appropriate experience, qualifications, skills, values and competence, and to be supported in their role.(16,22)

Governance and accountability:
- Effective governance strategies are important in ensuring accountability at individual, team and service levels.(7-9,23)
- It is important to foster a culture of continual learning and quality improvement at an organisational level; encouraging staff to share problems and concerns, promoting a just culture over blame and judgement.(7,8,22)

Types of documents identified:
- More countries are using overarching national documents that cover multiple population groups, across health services, or across health and social care services, rather than specific standards, guidance, strategies or policies focused on disability only.
- Most of the findings related to all age groups and were applicable to both adults and children.

Scoping review to identify the characteristics of person-centred care in residential services for children and adults with disabilities

A scoping review of peer-reviewed literature was conducted to identify and describe how peer-reviewed literature characterises person-centred care for children and adults with disabilities living in residential services. From the included articles, 20 definitions of person-centred care were identified, highlighting that person-centred care:

- places the person at the centre of their care (24-30)
- focuses on and respects the person's needs and preferences (25,26,28,31-34)
- supports the person to make decisions and meaningful choices, to participate in their own care, and to engage in society (25,27,29,31-34)
- involves a partnership approach with staff, family and friends, with the person at the centre (24,25,32,33)
- requires staff that are respectful, flexible, attentive, sensitive, motivated, and effective.(25,26,29,32-35)

Residential services for children with disabilities

The 2013 *National Standards for Residential Services for Children and Adults with Disabilities* include separate sections for children and adults. While the standard statements are broadly the same for adults and children, some features are age-specific. Notably there was limited data relating specifically to children with disabilities in residential care, during the course of this evidence review. While the findings set out in this report suggest that standards can apply equally to both children and adults, it has highlighted several key areas for consideration in relation to children, specifically. The aim internationally is to provide support so that as many children as possible live at home, in foster care, or in family-like environments, where they can maintain family and community supports.(16,17,19,20) There is a need to employ staff who have the right skills and training to ensure that children can be involved and centred in their own care and its planning in such a way that meets their needs and stage of development.(34) Children were also identified as needing more support when transitioning within and between services, especially when moving from child to adult services.(7,12,13,18,20,36-38)

Overall findings

The findings of each element of the evidence review were analysed, and the key findings and learnings for Ireland were identified. These findings are described in relation to the four HIQA principles of person-centred care, that is, a human rights-based approach, safety and wellbeing, responsiveness, and governance and accountability.(39) It is important to note that these four principles are interlinked and as such, there is some overlap, with some points relevant to more than one principle.

Principle 1: Human-rights based approach to care

In Ireland, the current *National Standards for Residential Services for Children and Adults with Disabilities* address a human rights-based approach to care, however the emphasis on this approach is limited. A key finding is that there is now a far greater emphasis on a human rights-based approach to care in services, in line with the UNCRPD and the range of developments in the sector.

It is recognised both nationally and internationally that people with disabilities have the same human rights as everyone else. The evidence shows the importance of placing the person with a disability at the centre of everything; this involves protecting and promoting their human rights, supporting them to have a voice, listening to them, and considering their preferences. People with disabilities living in residential services should also have autonomy, access to information in a way that suits their needs, and choice in relation to the care and support they receive. In addition, the evidence highlights the need for people with disabilities to be provided with a safe living environment and, in line with the person's wishes, to have the support and involvement of family and friends.

The evidence from all three elements of this review found that restrictive practices in residential services are a contravention of a person's basic human rights and should be avoided if possible. The evidence highlighted the need for staff to be made aware of the impact of restrictive practices on residents and to receive training in de-escalation techniques and the use of least restrictive practices.

Principle 2: Safety and wellbeing

The evidence emphasises the importance of supporting the physical and mental health of people with disabilities in residential services. This includes the right to feel safe and secure in a homely and inclusive living environment, where there are systems in place to prevent the risk of harm, and to ensure that if harm occurs or is likely to occur that it is stopped and reported as quickly as possible.

Both nationally and internationally, there is a general move away from large, congregated settings, to smaller community settings. These smaller living arrangements are found to directly benefit residents, providing them with more control and choice in their lives and improving their quality of life. Consideration of the size and design of a service, and how residents are grouped within a service were also found to be important. Nationally, it was found that institutionalised practices are still in place in some services, and there is a need for further improvements and a continued move towards more person-centred care.

The evidence found several areas for consideration, including person-centred approaches to planning that allow people to actively participate in developing and implementing their individual support plan. This collaborative partnership between the person and the service provider, involves the person in their own care and empowers informed decision-making and autonomy for residents. However person-centred planning heavily relies on the beliefs and attitudes of the staff involved. Consequently, staff training should be considered to promote a cultural shift within services in areas such as active support, person-centred planning, decision-making, and positive behaviour support. In relation to children, the evidence highlighted the importance of ensuring that children are engaged in this process in a way that meets their needs and stage of development. The need to support people to engage with their family and social networks and create opportunities for people to build and maintain relationships was highlighted.

There is consensus in the evidence that the person with disabilities should be placed at the centre of care, to ensure their needs can be identified and met, and that they receive the right care at the right time.

Principle 3: Responsiveness

The evidence identified that a responsive workforce, who are skilled, experienced and trained, who are clear about their roles and responsibilities, and have the resources to carry out their duties, was essential to providing responsive person-centred care. Additionally, the findings identified that a shift from task-oriented ways of working to a more a person-centred approach is required, where staff work flexibly to adjust to the persons' current needs, rather than prioritising staff needs and tasks.

The evidence highlighted the importance of communication, trust, continuity of care, and cooperative partnerships between people using services, service providers and families. The importance of staff who foster positive, caring and trusting relationships with people living in residential services, and learn each person's preferred communication methods was emphasised. This ensures that the person has confidence in the care being provided, in the level and quality of information being shared about them, and in the coordination and continuity of their care. Additionally, the importance of good, open lines of communication within organisations allow responsive action when required was highlighted.

The evidence indicated that people with disabilities, and children in particular, need support when transitioning within and between services. Examples of transitions include transitions between child and adult services, from home to residential services, or from residential services to independent living.

To ensure transitions are planned and supported, it is important to involve the person at all stages;

- to assess the appropriateness of the new setting
- to share information in a way that suits the person
- to develop pathway assessments and pathway plans
- to keep all interested parties informed at each stage of the process.

Principle 4: Governance and accountability

The evidence highlighted the importance of effective governance strategies to deliver high-quality services, ensuring person-centred care and accountability at individual, team and service levels. In addition, effective governance strategies are necessary in residential services to support continuous learning, quality improvement and the implementation of relevant standards.

In Ireland, there has been a greater focus on effective governance and management of residential services; many providers have an increased focus on effective governance arrangements that improve levels of compliance, quality of life for the residents, lines of communication within a service, and the providers' ability to respond to crises.

The evidence found several key characteristics to consider, including person-centred coordination of care, to ensure that people do not experience gaps in their care and support. There is a need to ensure that people with disabilities have equitable access to services, and to the buildings that house services, when they need it. Accountability in relation to the safe and appropriate grouping of people with disabilities within residential services was highlighted in relation to age, gender, and consideration of those with challenging behaviour.

The evidence highlighted the need for services to build a culture that is based on safety and trust, that prioritises improvement over blame and judgement, where staff are open and honest, and there is genuine interest in the wellbeing of all colleagues. The need to adopt and implement the principles of person-centred care at an organisational level was also identified as a requirement for systems and cultural transformation within services to take place. An example of good practice identified is the implementation of a holistic approach to person-centred planning within the service that is understood and implemented by all staff.

Conclusion and next steps

This evidence review has highlighted that there are key areas of change, on a national level, since the publication of the *National Standards for Residential Services for Children and Adults with Disabilities* in 2013.(1) The review of standards and related international documents identified key areas that should be considered in any update of the standards. The peer-reviewed literature provided additional up-to-date evidence and highlighted important characteristics of person-centred care for people with disabilities living in residential services.

This evidence review is one part of the HIQA standards development process and will inform next steps in relation to the *National Standards for Residential Services for Children and Adults with Disabilities* in Ireland.

When developing national standards, HIQA also includes engagement with stakeholders through an advisory group, focus groups and public consultation. The outcomes from this evidence review, and the stakeholder engagement process, would inform any update of the standards.

Summary of the overall key findings

This review has highlighted that there are several key areas that should be considered in an update of the *National Standards for Residential Services for Children and Adults with Disabilities* to ensure alignment with a human rights-based approach to care, and legislative changes in Ireland:

Key findings relating to a human rights-based approach:

- A human rights-based approach should form part of the everyday practices within residential services for people with disabilities.
- The current *National Standards for Residential Services for Children and Adults with Disabilities* address a human rights-based approach to care, however the focus on this is limited. As a result of key changes in the sector since 2013, a more positive culture has emerged in residential services for people with disability in Ireland, which prioritises a human rights-based approach to care and has contributed to improved quality of life for residents.
- However, nationally it was found that some services still have practices in place that infringe on residents' rights to freedom of movement, supported decision-making, and choice and control in their daily lives. Further improvements are therefore needed to fully transition to a human-rights based approach to care and support.
- There is a need for further reform in policy and legislation for Ireland including the need for adult safeguarding legislation and reform of the Health Act 2007 and associated regulations to reflect a more human rights-based approach.

Key findings relating to safety and wellbeing:

- Important characteristics of services that focus on safety and wellbeing include those relating to safeguarding, person-centred planning, timely assessments of need and appropriate resident groupings.
- In Ireland, where institutionalised practices are still in place in some services, the move away from congregated settings provides new opportunities for the concepts and characteristics that relate to safety and wellbeing to be considered.

Key findings relating to responsiveness:

- Important characteristics related to responsiveness include a workforce who are well trained and work in a person-centred way, good communication between staff and people using the service, and continuity of care and smooth transitions within and between services.

- It is important for staff to shift from a task-oriented way of working to a person-centred way of working, where the person and their needs take priority over staff needs and tasks, and staff provide appropriate support, fostering partnerships with their friends and family, as appropriate.

Key findings relating to governance and accountability:

- The evidence provided more clarity on what a well-governed, accountable service looks like. This includes adopting a culture within the organisation that promotes continuous learning in a supportive environment, implementing the principles of person-centred care and ensuring the coordination of care in and between services, at an organisational level.

1. Introduction

1.1 Background

It is estimated that 16% (1.3 billion people) of the global population experience disability.(41) In the European Union, this figure is estimated to be 101 million, with over one million people living in institutions§.(42,43) In 2024, 8,036 people engaging with disability services in Ireland lived in residential care. Of these, 7,844 were adults and 192 were children. Additionally, overnight respite was provided to 5,310 people, of which 4,202 were adults and 1,108 were children.(44)

The World Health Organisation (WHO) *Global report on health equity for persons with disabilities* published in 2022 stated that people with disabilities have an equal right to the highest attainable standard of health. However, despite substantial progress in many countries, there is still disparity in the standard of care, owing to the persistent health inequities that persons with disabilities experience.(41)

Service delivery has shifted from a system-centred approach to a person-centred approach in the last few decades.(30) Person-centred care is a holistic approach to care, in which people are provided with the support needed to enable them to participate and make decisions about their own care, and care is tailored to their individual needs.(45) A person-centred approach to care has been shown in some studies to have many positive benefits, delivering better outcomes for those receiving care, including people with disabilities.(45,46) However, a systematic review in 2016 on the effectiveness of person-centred planning for people with intellectual disability concluded that clearer descriptions of person-centred planning and its components are needed.(47)

Setting national standards is a quality improvement intervention deemed effective in establishing consistency in the delivery of high-quality care.(48) National standards for health and social care promote practice that is up to date, evidence-based and effective.(49) In Ireland, the Health Information and Quality Authority (HIQA), is an independent statutory authority established to promote safe, high-quality care for people using health and social care services.(50) Informed by evidence and best

---

[§] The term 'institution' is generally not used in Ireland, rather the term residential service or residential care setting is generally used. The European Expert Group on the Transition from institutional to Community-Based Care (EEG) defines an institution as being any residential care where:

- residents are isolated from the broader community and or compelled to live together
- residents do not have sufficient control over their lives and over decisions which affect them
- the requirements of the organisation itself tend to take precedence over the residents' individual needs.

international practice, HIQA has statutory responsibility for setting standards for health and social services and has a role in monitoring compliance against those standards.(50)

In 2013, HIQA published the ministerially-approved *National Standards for Residential Services for Children and Adults with Disabilities*. These standards were developed using an eight-theme framework to set out what a good-quality, safe residential service for people with disabilities should be. The standards include separate sections for children and adults. While the standard statements are broadly the same for adults and children, some features are age-specific.(1) In 2021, HIQA developed a standards development framework with four principles with the goal of achieving person-centred care in health and social care services; a human rights-based approach; safety and wellbeing; responsiveness; and accountability.(39) Any new or updated standards developed by HIQA will be developed under this framework.

Since 2013, there have been significant legislative advancements, with an increased focus on a human-rights based approach to care, including the ratification of the United Nations Convention on the Rights of Persons with Disabilities (UNCPRD) in 2018 and the commencement of the Assisted Decision-Making (Capacity) Act 2015.(4,5) As a result of these legislative changes, updating of the *National Standards for Residential Services for Children and Adults with Disabilities* is recommended.(1)

Under the Health Act 2007, the Chief Inspector of Social Services within HIQA is legally responsible for the monitoring, inspection and registration of designated centres for children and adults with disabilities.(2) The role of the Chief Inspector is to ensure that providers deliver a safe, quality service to residents. To be registered to operate, designated centres must meet the requirements set out by the Health Act 2007, associated regulations, and national standards.(51) Designated centres have been regulated by HIQA since 2013. More information on the regulation of designated centres for children and adults with disabilities can be found in Chapter 2 of this evidence review (Overview of the regulation of residential services for children and adults with disabilities in Ireland).

In order to understand developments in relation to residential services for children and adults with disabilities, since the standards were published in 2013, HIQA undertook an evidence review of relevant national and international documents, and peer-reviewed literature. In line with HIQA's process for updating existing standards, this review is limited to an overview of the regulation of residential services for people with disabilities in Ireland, a review of relevant standards internationally and a scoping review of peer-reviewed literature. The aim of this evidence review is to identify important areas for inclusion in any updated standards.

1.2 Standards development framework

Since 2021, all national standards developed by HIQA are set out according to the principles of person-centred care outlined in the *Standards Development Framework: A principles-based approach*.(52) These principles are:

- **A human rights-based approach** – The principle of a human rights-based approach means that health and social care services respect, protect and promote the human rights of the person receiving care and support, at all times. Human rights are the basic rights and freedoms that all people should enjoy and everyone is entitled to have their human rights respected and protected. These human rights, in a health and social care context, include the right to autonomy and to make informed choices, to be treated with dignity and respect and in an equal and non-discriminatory manner, the right to privacy, and the right to safety.
- **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. Health and social care services recognise that the safety of people receiving care and support in their service is paramount. Safety is essential to a person's overall health and wellbeing, both in terms of providing safe care and support by preventing unnecessary harm caused by medical or social care interventions, and safeguarding people from abuse, neglect or other kinds of harm by taking preventative actions.
- **Responsiveness** – The principle of responsiveness includes both how health and social care services are organised to deliver coordinated care that meets the needs of those who use them, and the way staff identify, assess and respond people's needs in daily practice. Its aim is to ensure that individuals receive the right care and support at the right time and in the right place. Responsive services put people's needs first and work collaboratively, both with the individual and other services when necessary, to identify, assess and respond to these needs, ultimately improving outcomes. Staff look at the whole person and their wider needs, and do not focus on meeting their presenting needs in isolation.
- **Governance and accountability** – The principle of governance and 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. Accountable services have a clear vision for their work, support their staff to deliver on this vision, work well with other relevant services, and regularly assess the impact of their work on those that they are caring for and supporting. Leadership and governance are essential to ensuring that services are accountable for the

> care and support they provide. Accountable services develop and implement an effective accountability framework at the highest level in the organisation to ensure that overall accountability for the delivery of services is clearly defined.(52)

Figure 1 below sets out the four principles and illustrates that the person receiving care and support should be at the core of everything, with each of the principles working together to achieve person-centred care and support. National standards developed by HIQA are also outcomes-focused, based on the outcomes that are important to people using the service. The *Standards Development Framework: a principles-based approach*, replaced the eight-theme framework which HIQA used to develop the *National Standards for Residential Services for Children and Adults with Disabilities* in 2013.(52)

Figure 1. Principles of person-centred care to underpin national standards for health and social care services

1.3 Structure of this report

This document sets out the findings of the evidence review on residential services for children and adults with disabilities under the following headings:

Chapter 2: Overview of the regulation of designated centres of residential services for children and adults with disabilities in Ireland

Chapter 3: Review of international standards and related documents for residential services for children and adults with disabilities

Chapter 4: Scoping review to identify the characteristics of person-centred care in residential services for children and adults with disabilities

Chapter 5: Discussion, conclusion and next steps.

2. Overview of the regulation of residential services for children and adults with disabilities in Ireland

2.1 Introduction

In 2013, HIQA commenced the regulation of residential services for people with disabilities in Ireland. To support this, HIQA published *National Standards for Residential Services for Children and Adults with Disabilities* in 2013, that set out what a good-quality, safe residential service for people with disabilities should be.(1,40) Under the Health Act 2007, the Chief Inspector of Social Services within HIQA is legally responsible for the monitoring, inspection and registration of designated centres for children and adults with disabilities.(2) HIQA publishes reports detailing the inspections carried out in specific services and publishes overview reports to summarise the key findings from services across Ireland, during specific time periods.

In 2024, HIQA published an overview report on *10 Years of Regulating Designated Centres for People with Disabilities*.(3) The report sets out the impact of regulation from 2013 to 2024, detailing the main findings and learnings in key areas such as a human rights-based approach to care, safeguarding and protection, and governance and management as well as reflecting on current and future challenges for the sector.

2.1.1 Purpose of this chapter

The purpose of this chapter is to describe the regulation of residential services for people with disabilities in Ireland and identify the key changes in the sector since the publication of the standards in 2013. The findings will inform any update to the *National Standards for Residential Services for Children and Adults with Disabilities*.

2.1.2 Methods

In line with HIQA's process for updating existing standards, this national element of the review was limited to an overview of the regulation of residential services for people with disabilities and the key changes in residential services for children and adults with disabilities in Ireland, since regulation commenced in 2013. For the purposes of this chapter, key findings have been extracted from *10 Years of Regulating Designated Centres for People with Disabilities*, and from other key sources such as legislation and the *HIQA Regulation handbook: A guide for providers and staff of designated centres,* last updated in 2025.(2,3) Areas of significant change since 2013 are identified, and the findings are summarised in relation to the four principles that underpin person-centred care and support: a human-rights based approach to care, safety and wellbeing, responsiveness, and governance and accountability.(52)

2.2 Overview of the regulation of designated centres of residential services for children and adults with disabilities in Ireland and related legislation

This section provides a background and context to the regulation of designated centres in Ireland, including residential services for children and adults with disabilities and is set out under the following headings:

- the regulation of residential services for children and adults with disabilities
- United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)
- recent legislation related to HIQA's role.

2.2.1 The regulation of residential services for children and adults with disabilities

The Health Act 2007 sets out the functions of HIQA and the Office of The Chief Inspector of Social Services within HIQA.(51) The Act is the primary legislation governing the regulation of designated centres in Ireland and provides for a scheme of registration and inspection of residential services for persons with disabilities in need of care and protection.

The Act provides a definition of a 'designated centre' as an institution:

a. at which residential services are provided by the Executive, a service provider or a person that is not a service provider but who receives assistance under section 39 of the Health Act 2004 or under section 10 of the Child Care Act 1991
    i. in accordance with the Child Care Act 1991
    ii. to persons with disabilities, in relation to their disabilities, or
    iii. to other dependent persons, in relation to their dependencies,

or

b. that is a nursing home as defined in section 2 of the Health (Nursing Homes) Act 1990.(51)

The term 'residential services' used in the above definition is not itself defined in the Act and as such, the Chief Inspector has provided the care sector with a widely accepted and used interpretation.(53) In relation to residential services for people with disabilities, this term means:

> a ‘residential service’ is one that is comprised of both accommodation and care and or support services provided to children and adults with disabilities living in residential settings, on a short or long-term basis, whether or not it is their sole place of residence.(53)

The Health Act 2007 provides for the development of statutory regulations and national standards for residential services for people with disabilities.(51) Regulations made under this Act set out the minimum legal requirements that providers must meet to provide safe, quality care to residents. These regulations include:

- Health Act 2007 (Registration of Designated Centres for Persons (Children and Adults) with Disabilities) Regulations 2013, as amended
- Health Act 2007 (Care and Support of Residents in Designated Centres for Persons (Children and Adults) with Disabilities) Regulations 2013.(54,55)

Under the Health Act 2007, all residential services for children and adults with disabilities are required to be registered by HIQA as ‘designated centres’.(51)

At the time of writing, the current register of designated centres has 1,682 centres offering 9,299 places for people with disabilities, which includes respite centres. Of these, 156 centres were for persons 18 years old or younger, with a maximum occupancy of 691 young people.(56) Data from the National Ability Supports System (NASS) for 2024 reported that 8,036 people were living in a residential setting. Of these, 7,844 were adults and 192 were children. Eighty-nine percent (7,112) of those living in a residential setting had an intellectual disability.(44)

Once registered as a designated centre, these services are subject to requirements in the Act, associated regulations, and national standards.(57) The Health Act regulations set out statutory requirements in relation to the maintenance, care, support and wellbeing of residents, the staff employed, the premises, and the food served to residents.(55) Statutory requirements in relation to the information and records to be kept, the management and control of operations, and the notification of incidents and complaints are also outlined.(55)

The purpose of this regulation is to ensure that the human rights of people with disabilities living in designated centres are upheld; that they have a good quality of life and a safe place to live; and that those charged with providing the service are held to account for non-compliance to regulations.(3) Regulation also provides assurance to people with disabilities, their families, the public, and the State, that people living in designated centres are receiving the safe, high-quality care and support to which they are entitled.(2) In regulating services, HIQA applies a human rights-based approach to ensure that the human rights of residents are protected and promoted.(2)

In 2013, HIQA published *National Standards for residential services for children and adults with disabilities.*(1,40) These standards outline what providers must do to ensure safe and effective care for people living in residential and residential respite services and they provide the framework for HIQA to assess whether residential services are in line with the requirements of the Health Act 2007. The standards also provide those who use services and their families and or representatives with a guide as to what they should expect from residential services. Key themes addressed by the standards are individual support and care; effective services; safe services; health and development; leadership, governance and management; use of resources; responsive workforce; and use of information.

2.2.2 United Nations Convention on the Rights of Persons with Disabilities

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) is a UN treaty which affirms and protects the human rights of people with disabilities.(4) Ireland signed the UNCPRD in 2007 and ratified it in 2018, thereby committing to 'promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity'.(58)

The UNCRPD states that people with disabilities include:

> those who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others.(4)

The convention applies human rights principles from the UN Declaration on Human Rights to people with disabilities; it contains 26 Articles covering all areas of life, including, civil and political rights, equal recognition before the law, freedom from exploitation, violence and abuse, and social and economic rights in areas such as education, health care, employment and transport.(59) As a state party to the UNCRPD, Ireland is required to report regularly to the United Nations Committee on the Rights of Persons with Disabilities on how the rights it has set out are being implemented. The UNCRPD has influenced the development and implementation of national strategies such as the National Disability Inclusion Strategy (2017-2021) and the introduction of legislation such as the Assisted Decision-Making (Capacity) Act 2015; these developments focus on promoting human rights and place emphasis on ensuring the provision of person-centred services for people with disabilities.(5,60)

2.2.3 Recent legislation in Ireland related to HIQA's role

Legislation commenced in Ireland in recent years provides additional roles and powers for HIQA that will impact on the regulation of designated centres.(3) The Health (Miscellaneous Provisions) (No. 2) Act 2024 makes changes to the Health Act 2007 in relation to conditions of registration for providers, and the collection and maintenance of information from specified designated centres.(61) Commenced in 2023, the Patient Safety (Notifiable Incidents and Open Disclosure) Act 2023 sets out the requirement for providers to notify the Chief Inspector of particular incidents that occur in designated centres within specified timeframes, and gives the Chief Inspector a new discretionary function to review a specified incident.(2,62)

2.3 Key findings from the regulation of residential services for people with disabilities since 2013

The report, *10 Years of Regulating Designated Centres for People with Disabilities,* provided an overview of the regulation of designated centres for people with disabilities between 2013 and 2023 against the statutory regulations and the *National Standards for residential services for children and adults with disabilities.*(3) This report did not separate children's services from adult services. This section describes a number of key findings of this report that relate to:

- the voice of the resident
- a human-rights based approach to care
- staff training on human-rights based approach to care
- the process of general welfare and development
- governance and management
- current and future challenges.

2.3.1 The voice of the resident

The report highlighted that to ensure residents are supported to have a fulfilling life, it is essential to hear and understand their lived experiences.(3) While HIQA has always focused on the voice of the resident, there was a call for both HIQA and service providers to place more emphasis on the voice of residents, in a way that suits their needs and stage of development, and captures what it is like for them to live in a centre.(3)

The *10 Years of Regulating Designated Centres for People with Disabilities* report highlighted that since 2013, some improvements have been made, and increasingly the voice of the resident and their experiences are important aspects of regulation and the delivery of care within the centres they live in.(3) More providers have embarked on a culture of placing the resident front and centre of everything they do. Listening to the voice of the resident promotes key aspects of the UNCRPD, including equality and non-discrimination, and freedom of expression and opinion.(3,4) The report noted that gathering and listening to residents' views ensures continued focus on the provider's responsibility to uphold the human rights of residents and ensure that their choices and preferences are respected.(3) Keeping the resident's voice central to the delivery of care recognises that they are the experts on their own experiences, needs and wishes.

2.3.2 A human-rights based approach to care

The report highlighted that, before 2013, some residential services were providing poor care that infringed on people's basic human rights. Poor practices included residents being inappropriately restrained and being spoken about in a disrespectful manner by staff. Other more subtle breaches of human rights that were deeply embedded in the culture of services were found. For instance, while some residents may have had 'freedom from' certain things such as abuse or neglect, they often did not have the 'freedom to' do what they want, whether that be engaging in an activity, being part of the local community, or expressing themselves.

Since 2013, in line with the UNCRPD, HIQA has promoted a human rights-based approach in designated centres and encouraged providers to embed human rights-based principles into their everyday practices.(3) The report recognised that a significant shift in staff culture and increased awareness of people's human rights can directly benefit residents and have a positive impact on their lives.(3) Centres delivering a human rights-based approach to care provide a good quality of life for residents by ensuring:

- their human rights are protected and promoted
- their autonomy is respected and promoted
- they are actively involved in their community
- they can make informed decisions about what is important to them.

While many providers have moved towards providing a human rights-based approach to care, some centres still have practices in place that infringe on residents' rights to freedom of movement, supported decision-making, and choice and control in their daily lives.(3) Further improvements are therefore needed to truly transition to a human-rights based approach to care and support in centres.

2.3.3 Staff training on a human-rights based approach to care

Following ratification of the UNCRPD in 2019, HIQA in conjunction with Safeguarding Ireland, published *Guidance on a Human Rights-based Approach in Health and Social Care Services*.(3,63) This guidance is structured around the FREDA principles of

Fairness, Respect, Equality, Dignity and Autonomy.(63) Subsequently, in 2021, HIQA developed and launched the online learning course *Applying a Human Rights-based Approach in Health and Social Care: Putting national standards into practice*.(3,64) Staff in designated centres are encouraged by HIQA to use the guidance and complete the learning course, to embed human rights-based principles into their everyday practices and to provide high-quality care in their centres.(3)

Staff who had undertaken human rights training reported that it has encouraged them to think about risk for residents differently and enabled them to discuss the residents' choices with them. Staff were more knowledgeable about the needs of residents and the supports they required. Staff also informed residents about the FREDA principles and why they were important to their care.(3)

However, the report also found examples from recent years where there has been an absence of a human-rights based approach for residents in some centres. An example was described where recently admitted residents did not receive support with decision-making and the impact of the move on their wellbeing had not been fully considered. Therefore, there is a need for greater awareness of residents' needs to ensure that their human rights are kept to the fore, and that the care and support provided meets their individual needs.

2.3.4 The process of decongregation

In 2011, the Health Service Executive (HSE) published *Time to Move on from Congregated Settings: A Strategy for Community Inclusion.*(65) The strategy highlighted that congregated settings[**] are institutional in nature and not capable of providing the best outcomes for residents.(65) The strategy sets out a vision that all housing arrangements for people with disabilities should be in ordinary neighbourhoods in the community, with individualised supports designed to meet their individual needs and wishes. Since its publication, there has been an ongoing process of decongregation, with providers transitioning residents from large, campus-based settings into smaller living arrangements in the community.

Since 2018, the number of large centres providing care and support to 20 or more residents has dropped by nearly 65%, from 62 in 2018, to 22 in 2023. The number of smaller centres providing care to two to four people has increased by 81% in the same period, from 350 in 2018, to 635 in 2023 and the number of centres providing care to one person has more than doubled, from 45 to 99 in 2023.(3)

[**] Congregated settings are places where 10 or more people live together or are based in a campus-style setting.

In recent years, there has also been a shift towards providing individualised services for some people whose care needs may be high, or where the person prefers to live alone. This, in turn, has contributed to the increased number of designated centres nationally.(3)

In 2023, 25% of people with disabilities living in designated centres in Ireland were still living in congregated settings.(3) While group settings are appropriate for some individuals, the report highlighted that transitioning from congregated settings into designated centres in the community, is critical to improving outcomes and quality of life for people with disabilities and modernising services. Residents who have made this transition reportedly play an active role in their move; are happier in their new home; are more engaged with their new community; participate in and enjoy in-house leisure activities.(3)

2.3.5 The regulation of restrictive practices

Restrictive practices are defined in the Health Act regulations as the 'intentional restriction of a person's voluntary movement or behaviour'.(55) Restrictive practices are sometimes used in circumstances where a person represents a danger to themselves or others (for example, a physical hold to guard against aggressive behaviour).(3)

The report noted that, before 2013, restrictive practices were a common feature in many health and social care settings in Ireland. Poor practices identified included restraint measures being used for excessively long periods of time, inadequate records of when restraint measures were used, and incidents where release from a restraint was dependent upon staff availability.(3) Restrictive practices impact on the resident's right to freedom and their use should be informed by the UNCRPD and the residents' right to liberty and security of person, and their right to freedom from exploitation, violence and abuse.(3)

Since 2013, regulations have placed strict controls on the use of restrictive practices.(3,55) HIQA's training, guidance and thematic inspections on the use of restrictive practices in designated services has resulted in changes in practice and a culture change among staff working in designated centres.(3) Providers, management and staff are now more aware of what restrictions mean for residents. Reducing and eliminating restrictive practices has been found to contribute to increased liberty for people living in designated centres, while at the same time reducing the likelihood of abuse.(3) It is now widely recognised among providers that restrictive practices are a contravention of a person's basic human rights and should be avoided, if at all possible.(3)

2.3.6 Safeguarding and protection

People have a right to safety and security in their own home, including, in residential services.(3,40) Safeguarding means putting measures in place which protect the health, human rights and wellbeing of individuals, and that enable at-risk children and adults with disabilities to live free from abuse, neglect and harm.(66) HIQA's *10 Years of Regulating Designated Centres for People with Disabilities* highlighted that in the early years of regulation, several poor practices were found in relation to safeguarding in residential centres, including failure by managers to keep residents safe and to manage incidents appropriately.(3)

Since 2013, regulations have been used to protect residents and promote good safeguarding practices. Safeguarding in residential services for people with disabilities supports key aspects of the UNCRPD, including liberty and security, and freedom from exploitation violence and abuse among residents.(3)

In 2019, in collaboration with the Mental Health Commission, HIQA developed National *Standards for Adult Safeguarding* and these were approved by the Minister for Health.(19) The standards aim to support all health and social care services to improve their practice, to promote people's human rights, health and wellbeing, and to reduce the risk of harm, beyond basic regulatory requirements.(66) Following their publication, HIQA and the Mental Health Commission also developed and launched an online learning course to help front-line staff implement the standards, entitled *National Standards for Adult Safeguarding: Putting the standards into practice*.

Overall, the report found regulation of services against statutory regulations and the *National Standards for residential services for children and adults with disabilities*, along with associated initiatives that have focused on the area of safeguarding, have had a positive effect on safeguarding practices in centres, which ultimately reduces the likelihood of harm or abuse.(3) However, despite the progress in this area, there is still much to be done to ensure all residents are kept safe from harm. Safeguarding is a critically important aspect of care in residential services and as such, HIQA has recognised the need and called for adult safeguarding legislation.(3)

2.3.7 General welfare and development

The report set out that general welfare and development is about each person being supported to develop and maintain their sense of worth, personal relationships, and links with the community, in line with their wishes.(3) In 2013, institutionalised practices which prioritised the organisation's preferences over those of the individual resident, were identified as being in use in some centres, particularly in larger congregated settings. These included settings being overly clinical in nature, and the delivery of services being based on the work patterns of staff, rather than on the needs of residents.(3) These practices, which represent a medical model of care and support, can have a significant adverse impact on residents' quality of life, such as limiting their opportunity to develop their independence and to engage with the outside world.(3)

Since 2013, the provision of care has evolved, with most providers now embracing a more social model of care that is more person-centred and informed by human rights principles.(3) When residents are provided with continued support and are empowered by staff to undertake activities, such as becoming active members in their community and keeping connected to family, in line with their wishes, it has a positive impact and improves outcomes for the residents.(3) The report found that residents who receive adequate support from staff, engage in positive risk-taking, and exercise choice on things that are important to them.(3)

While the majority of providers have now taken on a more social model of care informed by human rights principles, the report noted that institutionalised practices are still in place in some centres and there is a need for further improvements and a continued move towards more person-centred care.(3)

2.3.8 Governance and management

The report highlighted that, in 2013, some providers were found to have inadequate governance structures at senior level, poor lines of accountability, and an unwillingness to improve or learn from inspection findings.(3) Institutionalised practices were identified, and some centres were infringing on residents' human rights, including the right to a safe place to live, and a good quality of life. Poor practices in these centres meant that residents were placed at risk.(3)

Since 2013, HIQA has worked with registered providers to drive improvements in governance and to assist providers to deliver higher quality services for residents. In this time, many providers have reviewed their governance and management structures and have undertaken actions to significantly improve the effectiveness of their governance arrangements.(3)

While this process took time, it has resulted in high levels of compliance in certain centres, and an improved quality of life for the residents living in those centres. The changes have meant that residents' human rights were prioritised and upheld, and they were supported to make choices about where and with whom they wished to live.(3)

It was found that providers who establish a strong human rights-based culture supported by robust governance oversight arrangements, significantly improve residents' quality of life. Providers who have good governance and management structures in place have been found to be capable of responding to crises, have good lines of communication within the service, and are focused on quality improvement.(3) They are also responsive and can act quickly. The governance and management structures in designated centres play a pivotal role in ensuring accountability. Critical to good accountability is ensuring that services are planned and resourced effectively by competent, responsive management and staff who listen to the voice of the resident.(3)

2.3.9 Current and future challenges

The report found that while the commencement of the regulation of residential centres in 2013 was challenging for many service providers, most providers have since sought to move beyond basic regulatory compliance and are seeking to embed a culture of ongoing quality improvement in how they deliver care and support in their designated centres.(3) While much progress has been made in improving quality in services and outcomes for residents since 2013, significant challenges were identified that the sector now faces and is likely to continue to face into the future.(3)

Currently, there is no overarching social care policy or legislation in Ireland that sets out a vision for how people should be cared for and supported into the future.(3) In 2024, the Department of Health and the then Department of Children, Equality, Disability, Integration and Youth published the *Action Plan for Disability Service 2024-2026*, which is a strategy that looks to reform the model of service delivery in the disability sector. The strategy seeks to increase capacity in community disability services and aims to create more person-centred forms of support.(67) The report suggested that the action plan can be a starting point for wider reform and a more comprehensive strategy encompassing all social care.(3)

Despite huge improvements in the safety and quality of designated centres for people with disability arising from regulation, the report has highlighted the need to reform the Health Act 2007 and associated regulations, which are not sufficiently underpinned by a human rights-based approach.(3) For example, the Health Act 2007 contains a narrow definition of a designated centre, which limits the regulatory protection of people with a disability to the confines of the centre only. Accordingly, HIQA has highlighted the need for a broader definition that takes a more holistic view of the supports that people with disabilities require, providing them with greater protection and enhancing their quality of life.(3,68)

New legislation, such as the Assisted Decision-Making (Capacity) Act 2015, is likely to have a significant impact on how people with disabilities can access their human rights and exercise choice.(3,5) The Act commenced in 2023 and includes a range of measures to support people who may need help with making decisions. This may present a challenge to registered providers, particularly where a person indicates that they wish to make changes to their living circumstances or care arrangements.(3)

The introduction of adult safeguarding legislation has been in development for several years and is supported by a number of stakeholders such as Safeguarding Ireland, the Law Reform Commission, and the Oireachtas Joint Committee on Disability Matters.(3) While some legislative and policy measures have been in place for many years to promote the welfare and protection of children in Ireland, specific legislation to safeguard adults at risk of harm is considered long overdue, and when introduced will place additional responsibilities on all those involved in the provision of health and social care services.(3)

The report noted that the ongoing national shortage of housing has impacted on the ability of registered providers to source suitable accommodation for residents who wish to live in smaller settings within the community.(3) The number of planned moves from congregated settings has slowed down in recent years because of a shortage of appropriate housing.(3) This is negatively impacting on people's quality of life as they cannot live in communities of their choosing. In 2023, HIQA advised the Oireachtas Joint Committee on Disability Matters that there is insufficient residential capacity in the system.(69) Subsequently, the committee recommended the redistribution of funding in Budget 2025, in line with UNCRPD, to deliver better outcomes for people with disabilities, and maximise people's capacity, independence and quality of life.(70)

The report also highlighted that it is widely recognised that there is insufficient capacity in disability services to enable planning for emergency action for children or adults who are in crisis circumstances.(3) Additionally, HIQA has no power to register what might be termed 'emergency placements', and this inhibits its ability to respond in crisis situations.(3)

2.4 Summary of key changes since the publication of the *National Standards for Residential Services for Children and Adults with Disabilities*

This section provides a summary of key changes that have come about since the publication of the *National Standards for Residential Services for Children and Adults with Disabilities* in 2013. The findings are summarised in relation to the four principles of person-centred care that underpin national standards developed by HIQA.

Principle 1: Human-rights based approach to care

- Since commencement of the regulation of residential services for children and adults with disabilities in Ireland in 2013, findings from HIQA's *10 Years of Regulating Designated Centres for People with Disabilities* indicated that a more positive culture has emerged in many residential centres which prioritise a human rights-based approach to care. This has contributed to improved quality of life for people with disabilities living in those residential services.
- Ireland signed the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2007 and ratified it in 2018, committing to 'promote, protect and ensure full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity'.
- The enactment of new legislation, such as the Assisted Decision-Making (Capacity) Act 2015, emphasises maximising a person's autonomy and is likely to have positive implications on how people with disabilities can access their human rights and exercise choice. However, the sector still faces significant challenges as there is no overarching social care policy or legislation in Ireland that sets out a vision for how people should be cared for and supported into the future. There is a need for adult safeguarding legislation and a need to reform the Health Act 2007 and associated regulations, as they are not sufficiently underpinned by a human rights-based approach.
- There is an increased focus on understanding and communicating the voice of the resident and their experiences, upholding their rights and ensuring that their choices and preferences are respected. More providers have embarked on a new culture of placing the resident front and centre of everything they do.
- Regulations have sought to place strict controls on the use of restrictive practices, resulting in changes in practice and a culture change among staff working in designated centres. It is now widely recognised among providers that restrictive practices are a contravention of a person's basic human rights and should be avoided if possible.
- Some centres still have practices in place that infringe on residents' rights to freedom of movement, supported decision-making, and choice and control in their daily lives. Further improvements are therefore needed to

fully transition to a human-rights based approach to care and support in centres.

Principle 2: Safety and wellbeing

- Regulation has placed a heightened focus on good safeguarding practices in residential services for people with disabilities, which ultimately reduces the likelihood of harm or abuse for residents. Despite progress in this area, there is still much to be done to ensure all residents are kept safe from harm.
- There has been an ongoing process of decongregation since 2013, with providers transitioning residents from large, campus-based settings into smaller living arrangements in the community or for some people, to individualised services based on their care needs and preferences. While group settings are appropriate for some individuals, this decongregation is critical in improving resident outcomes and quality of life and has contributed to an increased number of designated centres nationally. Institutionalised practices are still in place in some services and there is a need for further improvements and a continued move towards more person-centred care.

Principle 3: Responsiveness

- Many staff in residential services have undertaken human rights training. In centres where staff had completed such training, the residents' human rights were respected, they were actively involved in the running of the centre, and they took a lead role in making decisions about their own lives. There has been a greater focus on the general welfare and development of residents in many centres; this includes a focus on ensuring accessibility, education and participation in community and cultural life, recreation, leisure and sport.
- There has been a shift towards a social model of care, from a task-oriented way of working to a person-centred approach, informed by human rights principles.

Principle 4: Governance and accountability

- There has been a greater focus on effective governance and management of centres that improve levels of compliance, quality of life for the residents, and lines of communication. Many providers have reviewed their governance and management structures and have undertaken actions to significantly improve the effectiveness of their governance arrangements.

3. Review of international standards and related documents for residential services for children and adults with disabilities

3.1 Introduction

HIQA has conducted a review of standards, guidance, strategies or policies internationally that are relevant to residential services for children and adults with disabilities.(40)

3.1.1 Purpose of this chapter

The purpose of this chapter is to:

- identify relevant standards, guidance, strategies or policies internationally and describe the types of documents, the target audience, the population specified and whether implementation is mandatory in each relevant country
- highlight areas where lessons can be learned to inform any update to the *National Standards for Residential Services for Children and Adults with Disabilities*.

3.1.2 Methods

This review included a desktop search of 37 countries and a search of three academic and grey literature databases. Table 1 outlines the eligibility criteria that were applied when considering documents for inclusion in the review. The results are reported by the types of documents identified (for example, specific or overarching documents), and under the services they relate to (for example, disability care or social care) and then by country under each service. This approach was used to better understand how the documents apply to residential services for people with disabilities.

The level of detail reported for each document is based on the level of detail provided in the individual documents. Searching for additional evidence to verify details, was beyond the scope of this review for updating existing standards.

Table 1. Eligibility criteria for inclusion in the review of international standards and related documents

Inclusion Criteria	Exclusion Criteria
▪ Standards, guidance, strategies or policies relating specifically to residential services for people with a disability	▪ Documents reporting interventions or personal opinions, focused on non-disability groups, or not focused on residential services for people with disabilities.
▪ Overarching standards, guidance, strategy or policy documents that included people with disabilities**(71,72)** ††	
▪ Standards, guidance, strategies or policies currently in use.	

Search Strategy

The search for international evidence was undertaken between the 10 September and 25 October 2024 and consisted of the following steps:

- A search of the Embase database using the following search terms ('standards'/exp OR standards OR policy OR law) AND ('disability'/exp OR disability) AND (residential OR 'care home' OR 'institutional care'), no date limit was applied.
- A search of two grey literature databases (Core and Grey Matters); the search terms used were disability AND/OR residential OR care home OR standards OR policy OR guidelines OR legislations. The search was further refined using filters in relation to year published (2010-2024) and field of study (Medicine). The first 100 references by relevance were screened, the search was ended once 30 consecutive documents produced no documents of relevance.
- A review of the reference list from the *National Standards for Residential Services for Children and Adults with Disabilities* (2013) and the list of organisations identified in the HIQA *International review of the methodologies for developing national standards and guidance for health and social care services.*(1,72)

[††] In recent years, both nationally and internationally, there has been a move towards standards that are more high-level and overarching. Overarching standards are standards that cover all health and social care services that are providing care and support, whether by statutory, private, or voluntary service providers, or whether in primary, acute, residential, or disabilities settings. By providing a common framework for all health and social care services, overarching standards aim to promote clarity, consistency and continuity within and between services.

- A desktop search of 37 countries[‡‡] identified as countries who regulate and monitor health service standards, using the search terms 'Country X' AND disability standards AND residential care.
- Citation chasing; lists of references in any of the documents identified as relevant from the searches were searched for additional documents of relevance.

Results of search strategy

A total of 259 documents were considered potentially relevant; 44 documents from 16 countries were included for full text review, of those, 17 documents from nine countries outlined standards, guidance, strategies and policies relevant to residential services for children and adults with disabilities and were included in the review of standards internationally (Table 2).

No relevant documents were identified for three countries: Belgium, Costa Rica, and Cyprus. Twenty-five other countries (Austria, Chile, the Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Hong Kong, Hungary, Iceland, Israel, Italy, Lithuania, the Netherlands, Norway, Poland, Portugal, Romania, Singapore, South Korea, Spain, Turkey and the United States) were excluded; these countries had documents relating to the topic but they did not meet the eligibility criteria.

3.2 International standards and related documents included in this review

This section describes the international standards, guidance, strategy or policy documents that are relevant to residential services for children and adults with disabilities. Data was extracted from each document to identify who they apply to, the purpose, themes and or principles described, and if they are regulated against. In recent years, both nationally and internationally, there has been a move towards standards that are more high-level and overarching.(72) Taking this into consideration, documents that were population or service-specific and others that were more overarching, were included in this report. The documents are grouped according to the services they relate to:

1. Residential services for children and adults with disabilities – documents specifically related to people with disabilities in residential services.

[‡‡] These countries are: Australia, Austria, Belgium, Canada, Chile, Costa Rica, Cyprus, Czech Republic, Denmark, England, Estonia, Finland, France, Germany, Greece, Hong Kong, Hungary, Iceland, Israel, Italy, Lithuania, Northern Ireland, Netherlands, New Zealand, Norway, Poland, Portugal, Romania, Scotland, Singapore, Slovenia, South Korea, Spain, Sweden, Turkey, United States and Wales.

2. Residential services for the general population – documents related to residential services for a variety of population groups including children or the elderly, as well as those with disabilities.
3. Disability care – documents related specifically to disability care and support in all health and social care settings.
4. Social care – documents related to care and support in all health and social care settings.

Table 2. Documents included by country, document title, year published, document type in the review of international standards and related documents

	Country	Document Title	Year Published	Document Type
		Residential services for people with disabilities		
1	New Zealand	Where I live; How I Live(14)	2018	Strategy
2	Scotland	Care homes for people with physical and sensory impairment(13)	2011	Standard
3	Scotland	Care homes for people with learning disabilities(12)	2011	Standard
		Residential services for the general population		
4	Canada	Long-Term Care Services(22)	2023	Standard
5	England	Care and support statutory guidance(18)	2024	Guidance
6	New Zealand	Ngā paerewa Health and disability services standard(9)	2021	Standard
7	Northern Ireland	Residential Care Homes Minimum Standards(8)	2021	Standard
8	Northern Ireland	Minimum Standards for Children's Homes(16)	2023	Standard
9	Scotland	Getting it right for looked after children and young people strategy(20)	2015	Strategy

Country		Document Title	Year Published	Document Type
10	Scotland	Children and Young People (Scotland) Act 2014: Statutory Guidance on Part 9: Corporate Parenting(17)	2015	Guidance
11	Wales	The Regulation and Inspection of Social Care (Wales) Act 2016; Statutory Guidance(23)	2024	Guidance
		Disability Care		
12	Australia	National Disability Insurance Scheme (Quality Indicators for NDIS Practice Standards) Guidelines 2018(7)	2024	Guidance
13	England	Care and support of people growing older with learning disabilities(21)	2018	Guidance
14	England	Disabled children and young people up to 25 with severe complex needs: integrated service delivery and organisation across health, social care and education(19)	2022	Guidance
15	Sweden	Swedish disability policy – service and care for people with functional impairments(11)	2009	Policy
		Social Care		
16	Scotland	Health and Social Care Standards: My support, my life(10)	2017	Standard
17	Slovenia	Rules on standards and norms for social protection services (15)	2010	Guidance

3.2.1 Standards, guidance, strategies or policies for residential services for children and adults with disabilities

Three documents provided relevant strategies and standards specific to residential services for people with disabilities.(12-14)

1. New Zealand - *Where I Live; How I Live, Disability Support Services Community Residential Support Services Strategy*, 2018 to 2020 (2018).
2. Scotland - *National care standards: care homes for people with learning disabilities* (2011).
3. Scotland - *National care standards - care homes for people with physical and sensory impairment* (2011).

New Zealand

Where I Live; How I Live, Disability Support Services Community Residential Support Services Strategy, 2018 to 2020

In 2018, the Ministry of Health in New Zealand introduced a new residential support services strategy for people (both adults and children) with a disability, called *Where I Live; How I Live*.(14) The vision of the strategy was to optimise the independence and self-determination of people with disabilities, in line with the 'Enabling Good Lives' principles[§§].(73) This strategy applies to children and adults with a disability in residential services and the staff caring for them.

This strategy outlined themes which aimed to support people with disabilities to become independent and to live everyday lives in everyday places, like others at similar stages of life. This support was to be achieved by investing early in support for families and whānau,[***] building community and natural supports, relationship building between family and community, and person-centred and easy to use supports tailored to the individual with a disability.

Residential facilities are registered, managed and run by a care provider who is responsible for all aspects of the care provided. The strategy outlines specific outcomes, with planned evaluation and monitoring. No information regarding the findings of any evaluations or monitoring processes was identified.

Scotland

National care standards: care homes for people with learning disabilities and *National care standards - care homes for people with physical and sensory impairment*

In 2011, the Scottish Government produced two standards documents, one for people with learning disabilities (the term primarily used in the UK for people with an intellectual disability).(74) These are the *National care standards: care homes for people with learning disabilities*, and one for people with physical and sensory impairments, *National care standards - care homes for people with physical and sensory impairment*.(12,13) Both documents are very similar, and have the same principles, follow the same format, and are regulated in the same way.

[§§] Leaders in the disability community in New Zealand developed the Enabling Good Lives (EGL) approach with the intent of shifting power and authority from government to people with disabilities and their families. The EGL vision and eight principles are based on respect towards people with disabilities and their families culminating in trusting them to be decision-makers in their own lives.

[***]Whānau is the Māori language word for the basic extended family group and encompasses three or four generations.

The standards were developed from the point of view of the children and adults who use the services and are grouped under headings which follow their journey through the service: before moving in, settling in, day-to-day life, and moving on. The standards apply to both the people with disabilities and the providers and managers in the care settings.

The principles identified include the right be treated equally, with dignity and respect; to enjoy social relationships; to have privacy and property respected; to make informed choices; to feel safe and secure in all aspects of life; to be free from exploitation and abuse; to make full use of the resources available; to live an independent life; and to be able to complain effectively without fear of victimisation.

The Care Inspectorate is the regulatory body for care services in Scotland. It regulates a range of care and support services including child minding and or child day-care, adult day care, care homes, care at home and housing support services.(75) Under the Regulation of Care (Scotland) Act 2001, the Care Inspectorate registers and inspects the care services who apply the standards for residential services for people with disabilities in practice. The Scottish Social Services Council regulates the social service workforce, including staff working in residential services, and promotes and regulates workforce education and training. The regulations are mandatory.(76)

3.2.2 Standards, guidance, strategies or policies for residential services for the general population

Eight documents provided standards, guidance, or strategies relating to residential services for the general population which also applied to people with disabilities.(8,9,16-18,20,22,23)

1. Canada - *CAN/HSO 21001:2023 (E) Long-Term Care Services* (2023).
2. England - *Care and support statutory guidance* (2024).
3. New Zealand - *Ngā paerewa Health and disability services standard* (2021).
4. Northern Ireland - *Residential Care Homes Minimum Standards* (2021).
5. Northern Ireland - *Minimum Standards for Children's Homes* (2023).
6. Scotland - *Getting it right for looked after children and young people strategy* (2015).
7. Scotland *- Children and Young People (Scotland) Act 2014: Statutory Guidance on Part 9: Corporate Parenting* (2015).
8. Wales - *Regulation and Inspection of Social Care (Wales) Act 2016; Statutory Guidance* (2024).

Canada

CAN/HSO 21001:2023 (E) Long-Term Care Services

The Health Standards Organization (HSO) is the standard development organisation used by the Standards Council of Canada. The HSO states that it uses a rigorous public process in developing standards and focuses on developing evidence-based health and social service standards.(77) In 2023, the HSO published the *CAN/HSO 21001:2023 (E) Long-Term Care Services* standard as a revision of the 2020 standard of the same name.(22) This standard provides long-term care (LTC) home teams, leaders, and governing bodies[†††] with criteria and guidelines in relation to governance, quality of life, quality and safe care, competent workforce, and a culture of quality improvement.

The HSO has developed guiding principles for people-centred care that include planning and delivering care that has integrity and relevance, allowing mutual understanding of people's goals, needs and preferences, communicating and sharing timely, complete, and accurate information to enable people to participate effectively in care and decision-making, ensuring equitable access to care, and promoting continuous learning and quality improvement.

The target audiences for the use of this standard include LTC home residents, substitute decision makers,[‡‡‡] essential care partners, the workforce, leaders, and governing bodies. The standard refers to people with disabilities, cognitive impairment and an intellectual disability. The defined resident population for this standard is adults who live in LTC homes.

The governing body of the LTC home ensures a current strategic plan guides the delivery of services and complies with obligations stated in relevant laws, regulations, contractual arrangements, and inspection and accreditation reports.(22)

[†††] In Canada, this is a body that holds authority, ultimate decision-making power, and accountability for an organisation and its services. This may be a board of directors, a council, a Chief and Council, or another decision-making body. A governing body may work independently or with government in jurisdictions where government is responsible for one or more governance functions.

[‡‡‡] A person or persons who have legal authority to make a care decision for a resident if the resident is incapable of making the decision for them self. Depending on the jurisdiction, a substitute decision maker may be referred to by other terms, such as health care representative, agent, proxy, personal guardian, committee of the person, temporary decision maker, or attorney for personal care.

England

Care and support statutory guidance

The Department of Health and Social Care in England produced a *Care and Support Statutory Guidance* document in 2024 relating to the general care supports available to all people requiring support.(18) The aim was to help people achieve the outcomes that matter to them in their life, by focusing on their needs and goals and general wellbeing, as outlined in the Care Standards Act 2000[§§§].(78)

This guidance covers issues such as promoting wellbeing to avoid developing the need for care and support, accessing preventative supports, maintaining and sharing information relating to care and support, independent advocacy, financial arrangements, person-centred care and support planning, safeguarding, transitioning to adult care and support, and continuity of care.

This guidance is intended for use by providers, and people using the supports and their families. It includes some details of specific supports for children and adults with a disability in residential services and transitioning from child services to adult residential services. Case studies within the document give examples of how the care and support would work for people with disabilities. For example, a case study outlined how a person with disabilities was identified by care staff as being at risk of becoming isolated and depressed, and how they were supported to have the confidence to engage in part-time work to address this.

This statutory guidance outlines the roles of the local authorities and the Care Quality Commission (CQC) as the independent regulator of health and social care services in England, in relation to the quality of the services and the continuity of care and support provided by the providers.(79)

New Zealand

Ngā paerewa Health and disability services standard

In New Zealand, the *Ngā paerewa Health and disability services standard* was published by the Ministry of Health in 2021 and came into effect in early 2022.(9)

[§§§] The Care Standards Act 2000 established a National Care Standards Commission; to make provision for the registration and regulation of a range of agencies, clinics, hospitals and services including children's homes, care homes, residential family centres, independent medical agencies, fostering agencies, and voluntary adoption agencies; to make provision for the regulation and inspection of local authority fostering and adoption services.

The standard is outcome-focused, reflects person-centred care, and is designed to empower people to make decisions about their own care and support to achieve their goals. The five key principles include achieving health equality, accessible health and disability services, choice and control through partnerships, best practice through collaboration and standards that increase positive life outcomes.

The standard has six themes - our rights; workforce and structure; pathways to wellbeing; person-centred and safe environment; infection prevention and antimicrobial stewardship; and restraint and seclusion.

The standard is applicable to a wide range of specialties, age groups and services, both public and private, within the health and disability sector, including providers of residential disability care.

Standards New Zealand is the national standards body in New Zealand which develop and publish standards and standards-based solutions. They work with stakeholders from a variety of sectors to develop new standards, update existing standards, or adopt overseas standards for New Zealand industries. They do not check compliance or issue certifications of compliance.(80) Disability service providers can opt to be registered and accredited by Joint Accreditation System of Australia and New Zealand (JASANZ)[****].(81) The Ngā paerewa Health and disability services standard applies to the providers of disability care and is overseen by Standards New Zealand. Every service or person who implements this standard is expected to be knowledgeable about, and comply with, the duties set out in it.(9)

Northern Ireland

Residential Care Homes Minimum Standards

The Department of Health in Northern Ireland produced the *Residential Care Homes Minimum Standards* for adults in 2021. These standards set out the values that should be embedded in practice and include: dignity and respect; independence while protecting against unreasonable risks; human rights that are safeguarded and actively promoted; equality and diversity that is valued and respected; choice that is based on clear and accurate information; informed consent; enabling and supporting to lead full and purposeful lives; free from exploitation, neglect and abuse; privacy, safety and confidentiality.(8)

[****] An organisation that accredits the organisations that certify businesses, products, systems, and services. This ensures that certifications are backed by a government backed, reliable and internationally recognised process.

It is expected that when these values are integrated into all aspects of planning, delivery and review of services, and the minimum standards are being met, the home will be a resource that delivers the best possible outcomes for residents living there.

The standards were developed with the help of residents, their representatives, providers, staff, professionals, inspectors and commissioners. The standards were also subject to a full public consultation process. The standards specifically mention those with physical disability or sensory impairment, and those who might require behavioural management. There are 35 standards in all and a detailed section that sets out the requirements that must be met by statutory, voluntary and private providers of residential care homes to obtain registration.(8)

The standard statements and associated criteria are designed to be measurable through self-assessment and inspection by the Regulation and Quality Improvement Authority (RQIA).(8,82) RQIA is an independent body responsible for monitoring and inspecting the availability and quality of health and social care services in Northern Ireland. It also encourages improvements in the quality of those services. Compliance with the regulations is mandatory.(83)

Minimum Standards for Children's Homes

The Department of Health in Northern Ireland also produced the *Minimum Standards for Children's Homes*, in 2023.(16) It has similar values to those outlined for adults in the *Residential Care Homes Minimum Standards* document and are intended to be firmly embedded and demonstrated in practice. The values specific to children with a disability include: reasonable adjustments to the care home, the same opportunity to make choices as other young people, provision of specialist equipment provided when required, and all care staff in the home should have appropriate experience, qualifications, skills, values and competence to meet the assessed needs of all children, including those with a disability.(16)

Articles 12 to 22 of the Health and Personal Social Services (Quality, Improvement and Regulation) (NI) Order 2003 set out the requirements that must be met by statutory, voluntary and private providers of children's homes to obtain registration.(84) RQIA takes the *Minimum Standards for Children's Homes* into account when regulating establishments and agencies.

Scotland

Getting it right for looked after children and young people strategy

The Scottish Government published *Getting it right for looked after children and young people strategy* in 2015, which set out the priorities to improve the lives of 'looked after children and young people'. 'Looked after children' are defined as children or young people who are being cared for by their local authority for more than 24 hours. The aim of the strategy was to have a care system where fewer children need to become looked after; where quicker decisions are made about permanence, that is where they will live permanently; where there is a substantial reduction in the number of children and young people under the care of their local authority; and where the outcomes for each child are improved. Children with a disability are included in this strategy and are identified as a group who are less likely to achieve permanence or to have their views heard.(20)

The strategy identifies three priority areas of work in relation to the care of children in residential services: early engagement, early permanence, and improving the quality of care. The approach focuses on building on the assets within families and communities to prevent children from becoming looked after where possible, with high quality support and assessment for families and looked after children, delivering permanence without delay, and with planned and supported transitions.

Local authorities are expected to monitor the quality of their care planning following the *Getting It Right for Every Child* policy, and to implement plans for improvement where necessary.(85) The *Quality framework for children and young people in need of care and protection* document published by the Care Inspectorate (the regulatory body for care services in Scotland) in 2022 outlines the expected quality of service provision across community planning partnerships and includes looked after children.(86) The framework is arranged under six high-level overarching domains: key outcomes, stakeholders' needs, delivery of services, management, leadership, and capacity for improvement.(86)

Children and Young People (Scotland) Act 2014: Statutory Guidance on Part 9: Corporate Parenting

The *Children and Young People (Scotland) Act 2014: Statutory Guidance on Part 9: Corporate Parenting* guidance document, published by the Scottish Government in 2015, is intended for those caring for 'looked after children', referred to as 'corporate parents', in care settings.(17) This guidance provides information and advice about how they should fulfil the duties set out in Part 9 (Corporate Parenting) of the Children and Young People (Scotland) Act to improve the care experiences and outcomes of looked after children and care leavers across Scotland.(87)

The guidance states that a child or young person's wellbeing considers the extent to which the child or young person is safe, healthy, achieving, nurtured, respected, responsible and included.(17)

This guidance acknowledges that the needs of looked after children and care leavers are often complex, stating that 'Some have physical and/or mental/learning disabilities. Safeguarding and promoting their welfare and wellbeing can, therefore, be challenging'.

Compliance with the statutory guidance is monitored through a variety of independent mechanisms, based on information provided by the corporate parents in relation to how they undertake their duties and responsibilities, including planning, collaborative working and reporting, which provides a layer of accountability.

This guidance is intended to be read alongside relevant legislative and policy guidance, which sets Corporate Parenting in the wider legislative context for looked after children and care leavers. These additional documents outline the child's journey into, through, and leaving care settings, and the principles that should be followed.(37,38)

Wales

Regulation and Inspection of Social Care (Wales) Act 2016; Statutory Guidance.

The Welsh Government updated the *Regulation and Inspection of Social Care (Wales) Act 2016; Statutory Guidance* document in 2024.(23) The purpose of this document was to set out guidance for service providers and responsible individuals, on how to meet service standard regulations for care home services, domiciliary support services, secure accommodation, and residential family centre services. The care home services are defined as 'providing residential accommodation for persons in need of personal care (by reason of old age, disablement, drug or alcohol dependence or mental disorder)'. Both children and adults are included in the regulations.(23)

The care home service is designed in consultation with the individual and aims to consider their personal wishes, aspirations and outcomes, and any risks and specialist needs, which inform their needs for care and support. This includes provision of staff with the knowledge, skills and competency to meet an individual's wellbeing needs, with appropriate language and communication skills, and continuity of care, with support from relevant agencies and specialists where required.(23)

Care Inspectorate Wales (CIW) act as the service regulator and uses the *Regulation and Inspection of Social Care (Wales) Act 2016; Statutory Guidance* document to inform its decisions to grant or refuse applications for registration as a service provider. CIW can take enforcement action against any registered service provider and responsible individual that does not adhere to the legal requirements.(88) CIW must be satisfied that prospective providers meet the standards of service provision and are accountable for service quality and compliance.(89)

3.2.3 Disability standards, guidance, strategies or policies

Four documents which provided guidance or policies in relation to disability, included limited information about residential services.(7,11,19,21)

1. Australia - *National Disability Insurance Scheme (Quality Indicators for NDIS Practice Standards) Guidelines 2018*.
2. England - *Care and support of people growing older with learning disabilities* (2018).
3. England - *Disabled children and young people up to 25 with severe complex needs: integrated service delivery and organisation across health, social care and education* (2022).
4. Sweden - *Swedish disability policy – service and care for people with functional impairments* (2009).

Australia

National Disability Insurance Scheme (Quality Indicators for NDIS Practice Standards) Guidelines 2018

The NDIS Quality and Safeguards Commission (NDIS Commission)[††††] publication, the *National Disability Insurance Scheme (Quality Indicators for NDIS Practice Standards) Guidelines*, outlines quality indicators for all NDIS funded supports and services.(7,90)

The section 'Specialist Disability Accommodation' within the guidelines, relates to providers of residential services for people with disabilities. The guidelines list outcomes related to access to, and choice and control of NDIS supports, including specialist disability accommodation dwellings, the dwelling enrolment process, and effective tenancy management.(7)

A framework document was developed in 2015 to guide the approach to developing the quality indicators: *National Disability Insurance Scheme Quality and Safeguarding Framework; Consultation report*.(36) People with disabilities living in

---

[††††] The National Disability Insurance Scheme Quality and Safeguards Commission (NDIS Commission), is an independent agency set up to embed, promote and incentivise continuous quality improvement in disability support.

supported accommodation or large residential centres, or exiting residential settings, have been identified in the framework as needing more support, as they may not have existing networks, may be more susceptible to abuse, and may be exposed to overuse of restrictive practices.(36)

The NDIS Commission takes responsibility for the regulation of NDIS providers and the requirements for providers seeking to become registered NDIS providers and maintains an online NDIS Provider Register. The register is available publicly and contains information on the compliance and enforcement actions taken by the NDIS Commission.(91)

The NDIS Practice Standards and Quality Indicators specify the quality standards to be met by registered NDIS providers.(90) The NDIS Code of Conduct promotes safe and ethical service delivery by setting out expectations for the conduct of those delivering services to NDIS participants, and applies to all providers, including those who are not registered with NDIS.(92) The national standards for disability services focus on rights and outcomes for people with disabilities and help to promote and drive a nationally consistent approach to improving the quality of a range of services, including NDIS providers.(93)

An Australian disability standards document, *National Standards for Disability Services*, was excluded from the review as it did not specifically refer to residential services.(94)

England

Care and support of people growing older with learning disabilities

The National Institute for Health and Care Excellence (NICE) was set up by the government in England to tackle the variation in availability and quality of healthcare in the NHS. NICE provide technology appraisals, clinical guidance and quality standards on treatments and care.(95) In 2018, NICE published the *Care and support of people growing older with learning disabilities* guidance. This guidance is aimed at providers of social care, health and housing support, commissioners, people with learning disabilities, their families, carers and advocates. It covers identifying changing needs, planning for the future, and delivering services including health, social care and housing. It also acknowledges that older people with learning disabilities have particular housing and social support needs.(21)

This guidance covers care and support in all settings, including people's homes and family homes, temporary accommodation, supported living, and specialist accommodation. It also covers day services, residential and nursing homes, and primary and secondary healthcare. The overarching principles cover access to services and person-centred care, communicating and making information accessible, decision-making, mental capacity and consent, involving the person with a learning disability and their family members, carers and advocates.(21)

It is not mandatory to apply the recommendations in this guidance. NICE provides implementation pointers and a comprehensive programme of support and resources to maximise uptake and use of the guidance. They suggest, when putting the guidance into practice, that providers review and monitor how well it is being implemented.(21)

Disabled children and young people up to 25 with severe complex needs: integrated service delivery and organisation across health, social care and education

In 2022, NICE published its *Disabled children and young people up to 25 with severe complex needs: integrated service delivery and organisation across health, social care and education* guidance.(19) This guidance aimed to encourage education, health and social care services to work together and provide more coordinated support to children and young people, and their families and carers. This guidance applies to education, health and social care practitioners and service providers, local authorities and health commissioners, disabled children and young people with severe complex needs, their families and carers.

The key principles state that education, health and social care practitioners should, in relation to the disabled child or young person with severe complex needs, always put their views, life goals, ambitions and preferences at the centre of planning and decision-making; take the views of parents, carers, and the people who know them best into account; take account of the cultural background; and tailor the support to their individual needs.

In relation to residential services for disabled children and young people with severe complex needs, this guidance states that providing care within their community would be most beneficial, improving their quality of life and maintaining their family and social relationships, but acknowledges that some children and young people require care in specialist residential placements. Local options should be explored before using long-distance placements.

This guidance recommends that specific outcomes be outlined in contracts with providers and contracts that only describe which services should be provided should be avoided. No other mention of regulation or monitoring was identified.(19)

Sweden

Swedish disability policy – service and care for people with functional impairments

In 2009 the Swedish government published the *Swedish disability policy – service and care for people with functional impairments*, with the principle that everyone is of equal value and has equal rights.(11) The Swedish Agency for the Coordination of Disability Policy (Handisam) was tasked with developing a coherent system for describing, monitoring and analysing the development and impact of disability policy and the living conditions of people with disabilities, and reporting the findings annually between 2011 and 2016 to inform future strategy periods.(96)

In 2021, the reports contributed to the publication of the *Strategy for systematic monitoring of disability policy in 2021-2031*. This strategy stated that implementation of the disability policy was to focus on four areas: enabling people with disabilities to function in everyday life on the same terms as people without disabilities; identifying shortcomings and obstacles that prevent this; providing individual support and solutions for individual independence; and preventing and countering discrimination.(97)

In Sweden, legislation provides for the regulation of health care and social services. All government agencies have an explicit responsibility for the implementation of disability policy. The National Board of Health and Welfare are responsible for issues relating to people with impairments.(11) Local authorities may interpret legislation relating to social services and shape their activities according to their own guidelines but also have a responsibility to include disability issues.(11)

3.2.4 Social care standards, guidance, strategies or policies

Two documents provided standards and guidance in relation to social care which included information in relation to people with disabilities and where they live.(10,15)

1. Scotland - *Health and Social Care Standards; My Support, my life* (2017).
2. Slovenia - *Rules on standards and norms for social protection services* (2010).

Scotland

Health and Social Care Standards; My Support, my life

The Scottish Government published *Health and Social Care Standards; My Support, my life* (10) in 2017 to replace the *National Care Standards* published in 2002 under section 5 of the Regulation of Care (Scotland) Act 2001.(76) A major change between the 2002 and 2017 standards was the inclusion of health, as well as care standards, therefore the standards were applicable across NHSScotland services, as well as those registered with the Care Inspectorate, and Healthcare Improvement Scotland (HIS). However, the 2017 standards were intended to be used to complement relevant legislation and best practice guidance applying to their service or sector, such as the specific standards for care homes for people with a learning disability, or physical and sensory impairment, published in 2011 and reported earlier in section 3.2.1 on Scotland.(12,13)

The objectives of the *Health and Social Care Standards; My Support, my life Standards* were to drive improvement, promote flexibility, and encourage innovation in how people are cared for and supported. They did not specifically refer to people with disabilities or residential services, but stated they applied to 'everyone' using a health or social care service. The standards were underpinned by five principles: dignity and respect, compassion, be included, responsive care and support, and wellbeing. Outcomes were phrased from the perspective of the people using the services.

The standards are regulated by both the Care Inspectorate, and Healthcare Improvement Scotland (HIS) in relation to inspections and registration. HIS has developed its Quality Assurance Framework to align with the 2017 Standards.(75,98)

Slovenia

Rules on standards and norms for social protection services

In Slovenia, the *Rules on standards and norms for social protection services* were published in 2010. In Slovenia, residential care, known as 'institutional care', includes care of children and adults with disabilities.(15)

These rules on standards included rules in relation to an assessment of need, and providing beneficiaries with information and counselling in relation to the services available to them. The services available included at home supports, equipment, training for families or staff caring for people with disabilities at home, and institutional care for those who cannot be cared for at home. To encourage active participation in social life and in the working environment, guidance, protection and employment was offered to those with disabilities, according to their abilities.(15)

Staff caring for people with disabilities at home are obliged to provide care in cooperation with a health centre or a provider with a concession in the field of health care, who maintain documentation on the care provided.(15)

Implementation of the *Rules on standards and norms for social protection services* is monitored by a nine-member Commission appointed by the Minister responsible for social affairs. The tasks of the Commission include interpreting the provisions, checking implementation annually, and drafting proposals for amendments and additions to the *Rules on standards and norms for social protection services*.(15)

3.3 Summary

This summary will be presented in two parts:

- key findings relating to the types of documents identified
- a summary of key lessons for Ireland.

3.3.1 Key findings relating to the types of documents identified

This section will look at the key findings related to the types of documents identified, including information on who they apply to, who they addressed and how they are implemented.

This review of international standards and related documents, relevant to residential services for children and adults with disabilities, identified 17 standards, guidance, strategies or policy documents from nine countries.

Overarching national documents

This review found that, increasingly, more countries are using overarching national documents that cover multiple population groups, across health services, or across health and social care services, rather than multiple specific standards, guidance, strategies or policies. Three documents related specifically to residential services for people with disabilities.(12-14) The remaining fourteen documents were overarching documents relating to residential, disability or social care services which included people with disabilities.(7-11,15-23)

For example, in Scotland the *Health and Social Care Standards; My Support, my life* (2017) states that the standards are for everyone and that, irrespective of age or ability, all are entitled to the same high-quality care and support.(10) Scotland was also the only country identified as providing, as Ireland does, standards specifically for residential services for people with disabilities. It has developed two standards documents, *National care standards: care homes for people with learning disabilities* and *National care standards - care homes for people with physical and sensory impairment*.(12,13) The overarching social care standards are intended to complement the existing legislation and the specific standards for residential care for people with disabilities.(10)

In Canada, the *CAN/HSO 21001:2023 (E) Long-Term Care Services* standards defined the population as people living in long-term care homes, which included care homes for people with disabilities, as well as care homes for children or the elderly.(22)

The target audience

The policies, strategies, standards and guidance examined varied in relation to who they addressed and how they were written. A number addressed all stakeholders, meaning the person with a disability, their family, the workforce and providers.(12-14,18,19,21) Some only addressed the workforce or providers.(7,9,16,20,99) Some were written with the person with a disability as the subject, and outcomes were phrased using 'I' or 'my' but were intended to be used by all stakeholders. For example, in Scotland, the *Health and Social Care Standards; My Support, my life* (2017) document uses statements such as 'I experience high quality care and support that is right for me'.(10) Four of the seven standards included in this review used outcome-based statements, three from Scotland and one from New Zealand.(9,10,12,13) The remaining three standards, two from Northern Ireland and one from Canada, used criteria-based statements.(8,16,22)

Other documents, although applying to all stakeholders, described what each individual person could expect from the service provider. For example, in Scotland, the *Care homes for people with learning disabilities* (2011) standards used statements such as 'You have the right to make decisions and choices about your life, and the support and care you receive'.(12) In Northern Ireland, the *Minimum Standards for Children's Homes* (2023) addressed the workforce only, and used statements such as 'Staff actively address the communication needs of children and young people, ensuring that suitable alternative methods, formats and languages are made available when required'.(16)

Population specified in the documents

Eleven of the documents related to everyone.(7-13,15,18,22,23) Two related to adults only.(14,21) Four related to children and or young people only; children and young people (up to 25 years old), were included in these four documents.(16,17,19,20) Three of these four documents relating to children and young people were overarching standards or strategy relating to residential care, and one was an overarching standard in relation to disability care. The documents outlined specific aspirations for children with a disability, in relation to where they lived, favouring living at home with their families, in foster care, or in family-like settings in their local community, with support, as ideal options.

In New Zealand, for example, one of the stated outcomes of the *Where I Live; How I Live, Disability Support Services Community Residential Support Services Strategy, 2018 to 2020* was to begin early by investing in families to support them to be aspirational for their child with a disability and to build community and natural supports.(14)

In both England and Scotland, in the *Disabled children and young people up to 25 with severe complex needs: integrated service delivery and organisation across health, social care and education* (2022) guidance, and in the *Getting it right for looked after children and young people strategy* (2015) respectively, the aim was to have a care system where fewer children needed to become looked after, improving their quality of life and maintaining their family and social relationships, where all local options would be explored before using long-distance placements, and where quicker decisions should be made about where they would live permanently.(19,20)

Mandatory or non-mandatory implementation

Implementation of the standards, guidance, strategies or policies varied between countries, with some documents being mandatory and closely monitored and evaluated, and others being used as non-mandatory recommendations. For example, in Scotland, the *Care homes for people with physical and sensory impairment* (2011) standards state that they are used to monitor the quality of services, and their compliance with the Regulation of Care (Scotland) Act 2001 and the regulations, which are mandatory.(13)

In New Zealand, a mixed approach is used within the *Ngā paerewa Health and disability services standard* (2021) which states that the word 'shall' refers to requirements that are essential for compliance with the standard, while the word 'should' refers to practices that are advised or recommended.(9) In England, the *Care and support of people growing older with learning disabilities* (2018) guidance states that it is not mandatory to apply the recommendations, and that the guidance does not override the responsibility to make decisions appropriate to the circumstances of the individual, in consultation with them, and their families, carers or guardian.(21)

3.3.2 Summary of key lessons for Ireland

This review of standards for residential care for people with disabilities internationally identified some key lessons for Ireland, which will inform any update to the *National Standards for Residential Services for Children and Adults with Disabilities*. These are presented under the four principles of person-centred care that underpin national standards developed by HIQA and include:

Principle 1: A human right-based approach

- In line with principles of person-centred care, there was consensus from all nine countries that people with disabilities have the same human rights as everyone else.

- Human rights were addressed under the topics of respect, dignity, consent, equality, inclusion, diversity, and empowerment.

Principle 2: Safety and wellbeing

- Safety and wellbeing was addressed by six countries (Australia, England, New Zealand, Northern Ireland, Scotland, Sweden), with a focus on supporting physical and mental health, the right to feel safe and secure, timely assessments of risk and need, zero tolerance of abuse, harm and neglect, and services that are tailored to people's needs, with a focus on wellbeing.
- A reduction in the level of congregated settings, and a corresponding increase in supported small residential services in the community, was a target for all six countries.
- Three countries (Australia, England, Scotland) addressed the issue of transitioning between services, either between child and adult services, from home to residential services, or from residential services to independent living. People with disabilities were identified as needing more support as they may not have existing networks, and may be more susceptible to abuse.

Principle 3: Responsiveness

- Canada, England, New Zealand, Scotland, and Wales addressed issues under the topic of responsiveness, including communication, trust, integration, continuity of care, responsive care, and support, cooperation and partnerships between service users, service providers and families. A responsive workforce, who are skilled, experienced and trained, and the resources available for them to carry out their duties, were also addressed.

Principle 4: Governance and accountability

- All nine countries addressed issues under the principle of governance and accountability including strategy, governance, management, responsibility, culture, information management, learning, compliance, and regulation. The current standards address governance and accountability under the theme of 'leadership, governance and management', describing it as directing and managing activities using good business practices, objectivity, accountability and integrity, at individual, team and service levels, and includes decision-making, risk management and meeting strategic, statutory and financial obligations.

4. Scoping review to identify the characteristics of person-centred care in residential services for children and adults with disabilities

4.1 Introduction

Person-centred care is a holistic approach to care, in which people are provided with the support needed to enable them to participate and make decisions about their own care, and care is tailored to their individual needs.(45) A person-centred approach to care has been shown in some studies to have many positive benefits, delivering better outcomes for those receiving care, including people with disabilities.(45,46) However, a systematic review in 2016 on the effectiveness of person-centred planning for people with intellectual disability concluded that clearer descriptions of person-centred planning and its components are needed.(47)

HIQA has conducted a scoping review of peer-reviewed literature to identify the characteristics of person-centred care in residential services for children and adults with disabilities.

4.1.1 Purpose of this review

The purpose of the scoping review, detailed in this chapter, was to identify and describe how peer-reviewed literature characterises person-centred care for children and adults with disabilities living in residential services. The specific research question addressed was:

- What are the characteristics and definitions of person-centred care in residential services for children and adults with disabilities?

4.2. Methods

The methods for this scoping review are briefly described in this section and more information on them can be found in the scoping review protocol, which is available at www.hiqa.ie. The protocol for this scoping review was registered with Open Science Framework and published on HRB Open.(100,101)

The scoping review was conducted in accordance with the Joanna Briggs Institute (JBI) methodology for scoping reviews.(102,103)

4.2.1 Eligibility criteria

Table 3 below outlines the research questions and the population, concept, context (PCC) framework.

Table 3. The research questions and the population, concept, context framework for the scoping review

Research question	Specific question	Population	Concept	Context
How does the peer-reviewed literature characterise person-centred care for children and adults with disabilities living in residential services?	What are the definitions and characteristics of person-centred care in residential services for children and adults with disabilities?	Children and adults of all ages with a permanent, or likely to be permanent, intellectual, sensory and physical disabilities.	Person-centred care or patient-centred care.	Residential services and residential respite services for children and adults with disabilities.

The population of interest were children and adults of all ages, with a permanent or likely permanent intellectual, sensory and physical disabilities, using residential services and residential respite services. Evidence from the perspectives of this population, their families and residential service staff members that related to person-centred care and or patient-centred care were included. Details of the eligibility criteria for the scoping review are in Appendix 1.

For the purposes of this review, the HIQA definition of residential services was used:

> A 'residential service' is one that is comprised of both accommodation and care or support services provided to children and adults with disabilities living in residential settings, on a short or long-term basis, whether or not it is their sole place of residence.

4.2.2 Search strategy

The database search followed a three-step strategy.(104) The first step involved undertaking an initial exploratory search of Medline via Ebscohost, Embase and Google to identify key articles on the topic.

In the second step, the librarian developed a comprehensive search strategy using identified keywords and index terms. The search was run in the following databases: MEDLINE Complete via Ebscohost, The Cochrane Library via Wiley, CINAHL Complete via EBSCOhost, Embase via Elsevier and PsycInfo via Ebscohost. The search strategy developed for Medline Complete is outlined in Appendix 2.

In the third step, the reference lists of all included sources of evidence were screened for additional studies using Citationchaser.(105)

The literature search was conducted in February 2025. The returns were catalogued according to the type of article and its source.

4.2.3 Evidence selection and screening

All identified citations were collected and screened against the eligibility criteria. Pilot screening at both the title and abstract and full text screening stages, was carried out in Covidence. Two reviewers worked independently to review articles and met to discuss the results. Any disagreements that arose between the reviewers at each stage of the screening process were resolved through discussion with a third reviewer.

The articles that met all inclusion criteria were included in the review. Reasons for exclusion of full texts were recorded and reported. The results of the search and the article inclusion process can be seen in Figure 2 PRISMA flow diagram.

4.2.4 Data extraction

Data extraction was completed using Microsoft Excel with a template and guidance form designed for this review.(104) The data extraction of articles was undertaken by one reviewer. A second reviewer checked the charted data to ensure it was accurate and complete.

4.2.5 Data analysis and presentation

The data is presented in section 4.4 as a narrative summary, and mapped to the four principles of person-centred care, including a human rights-based approach, safety and wellbeing, responsiveness, and governance and accountability.(52) Concepts that relate to more than one principle are discussed in the context of each relevant principle.

4.2.6 Selection of sources of evidence

Figure 2 depicts a PRISMA flow chart of the selection process for relevant articles and reasons for exclusion. A total of 958 articles were screened: 578 from databases, 98 from systematic reviews, and 282 from backward and forward citation searches. Full texts of 109 articles were assessed for eligibility, resulting in the inclusion of 23 articles in this scoping review.(24-35,106-116)

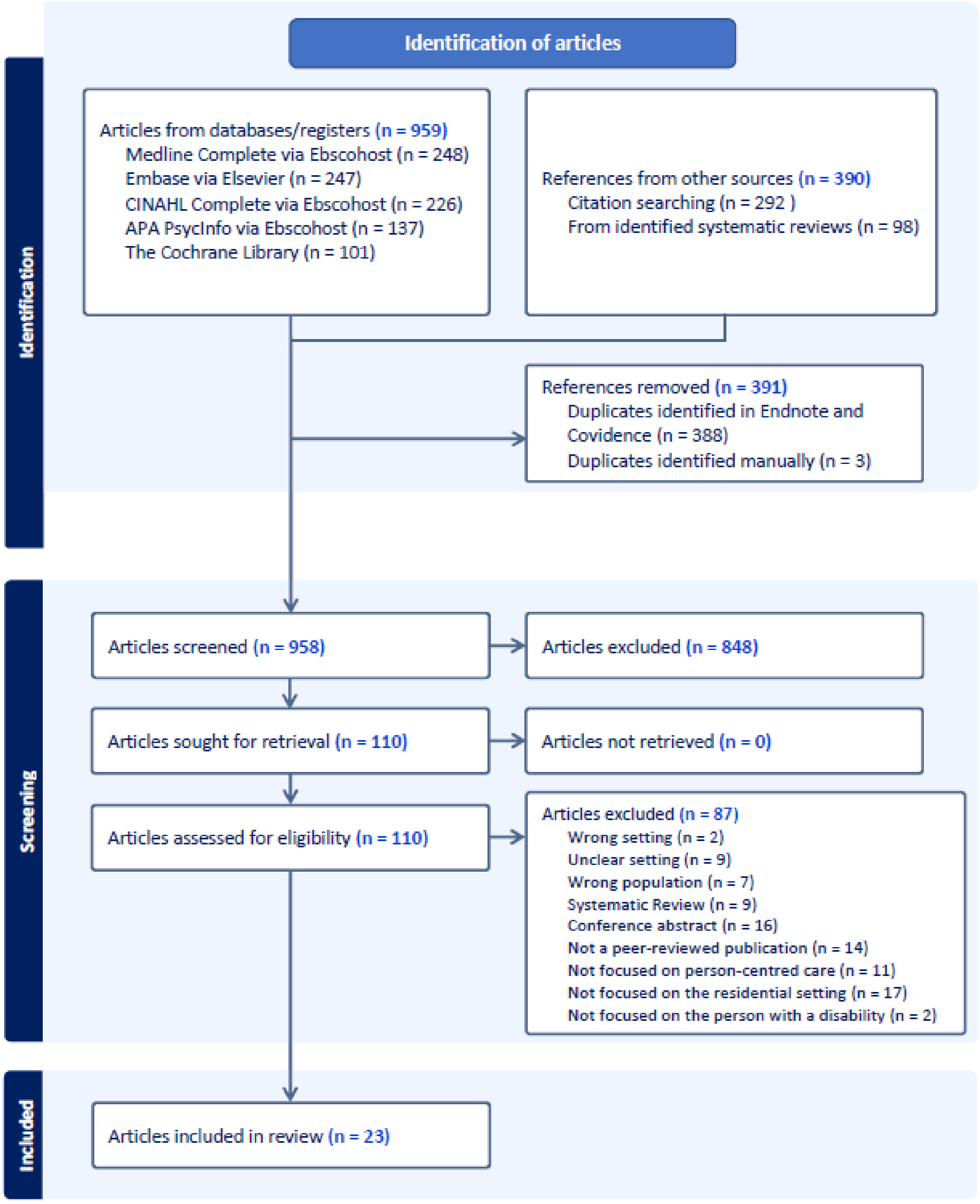

Figure 2. PRISMA flow chart illustrating the identification of articles in the scoping review

4.3 Results

This section describes the findings of this scoping review and the synthesis of results under the following headings:

- characteristics of sources of evidence
- definitions of person-centred care
- characteristics of person-centred care.

4.3.1 Characteristics of sources of evidence

Bibliography information, as well as findings relating to the aims and objectives of the articles, the study designs, populations included in the articles, the types of residential services, and the definitions and descriptions of person-centred care used in the articles were extracted. No assessment of the methodological quality of the sources of evidence was undertaken, as per scoping review methodology. The characteristics of the included articles are presented in Appendix 3.

The articles presented data from the multiple perspectives including the people with disabilities themselves (n=4), the staff caring for them (n=7), their family members (n=1), policymakers, experts in the field of disability, behaviour, frailty and ageing, and the researchers themselves (n=8). Eleven articles did not report the age of the people with disabilities who were the focus of the article.(28,30-33,108,111-113,115,116) In seven articles they were over 18 years.(25,29,106,107,109,110,114) In another four articles they were aged between 18 and 65 years.(24,26,27,35) One article reported on children between the age of 6 and 16.(34) All of the people with disabilities identified in the papers had an intellectual disability, and many had additional physical disabilities, medical conditions or impairments[‡‡‡‡]. Although person-centred care was referenced in all articles, ten articles did not provide a definition of person-centred care.(106-111,113-116) The remaining 13 articles provided between one and four definitions of person-centred care.

4.3.2 Definitions of person-centred care

This scoping review identified 20 definitions of person-centred care; 10 related to health and social care settings, two related specifically to people with dementia, and the remaining eight related specifically to people with disabilities. As all of the articles included in the scoping review were focused on people with disabilities, it

---

[‡‡‡‡] Physical, motor, sensory, or social impairments, for example reduced mobility, psychiatric conditions, challenging behaviour, or communication problems. Other medical conditions, for example epilepsy, dementia or severe psoriasis.

was assumed that the definitions related equally to people with disabilities. A table of the definitions of person-centred care is provided in Appendix 4.

Common terms and areas addressed appeared throughout the definitions. Figure 3 presents a word cloud of the common terms identified.

Figure 3. Common terms identified from the definitions of person-centred care in the scoping review

In the definitions provided, five main areas were addressed:

1. **The person at the centre** – ten definitions identified that the person should be at the centre of person-centred care. It was highlighted that each person was unique or individual, with person-centred care focused on getting to know the person, understanding the world from their perspective, and identifying their strengths, abilities, and capacities.
2. **Personal needs and preferences** – seven definitions referred to the importance of identifying, focusing on, or respecting the person's needs. Other terms related to needs included: wants, preferences, goals and aspirations. These needs were identified as coming from the persons' own personal social determinants of health.
3. **Support to participate in their own care and engage in society** – six definitions stated that the person should be supported to make decisions, meaningful choices, or to participate in their own care. Another definition used more active terms such as; 'to promote and facilitate opportunities to make meaningful choices'. The definitions highlighted the need for staff to

shift from task-focused to more supportive care, and for organisations to provide supportive social environments, so that the person was enabled to contribute to, or engage in society, to live their life according to their needs, with family and friends.

4. **Partnerships** – four definitions used the term partnership to describe the approach used to involve the person in decisions, with respect and understanding. Three other definitions used the terms relationships or collaborations. Members of partnerships, with the person at the centre of person-centred care, included service providers, healthcare professionals, care staff, family, and friends.
5. **Role of staff** – although not specifically mentioned in most definitions, eleven definitions were presented from the perspective of staff. Terms used along with 'staff' included: carers, healthcare practitioners, providers, or services. The descriptions of the actions of staff included: working practices, everything we do, supports for, care of, care for, approaches and practices. To achieve person-centred care, the definitions identified that staff needed to be respectful, flexible, attentive, sensitive, motivated, and effective. Beliefs, attitudes and expectations about the human rights of the person being cared for, and an assertion of the absolute value of all human lives, regardless of age or cognitive ability, were identified as traits that staff should have.

4.3.3 Characteristics of and strategies to support person-centred care

In total 111 characteristics of person-centred care were identified from the 23 articles. The characteristics were mapped to the four principles of person-centred care. It is important to note that the four principles of person-centred care are interlinked and as such there is overlap with some characteristics mapped to more than one principle. The characteristics mapped to each principle are discussed under a number of concepts and presented in the order of those with most characteristics. The list of characteristics, with the duplicate characteristics identified, and the principles and concepts to which they were mapped, is provided in Appendix 5.

Principle 1: A human rights-based approach

There were 36 characteristics mapped to the principle of a human rights-based approach. These characteristics are grouped into five concepts:

1. autonomy
2. promoting and protecting human rights
3. the living environment
4. support to understand relevant information
5. involving family and friends in line with the person's wishes.

Autonomy

Fourteen characteristics were grouped under the concept of 'autonomy'. Autonomy in relation to person-centred care was described using terms such as empowerment, inclusion, independence, choice and control, in relation to where and how a person lived, and the care and support they received.(25,109,112) The need for staff to support people with disabilities to have a voice was highlighted.(24,32,33) This support needed to be individualised, taking into consideration the individual's communication style, abilities, knowledge, strengths, capacity for choice, and overall interest in becoming empowered.(115) This may at times be difficult for staff, for example, one study noted that some older people may have reduced interest or engagement in making their own decisions and speaking up for themselves, as well as a reduction in the skills required for empowerment or self-advocacy.(109) Children were identified as requiring particular support in relation to engagement in their support plans.(34)

The findings show that there is a need for staff to focus on the person's perspective to better understand their wishes, needs and behaviours.(31,115) Staff need to respect that people have opinions, feelings, wishes, and preferences in relation to their care and activities, and their level of participation in activities.(24,32,33) For example, when attending respite care, people had very clear views on who they would like to be grouped with in respite and their level of involvement in planned activities.(25)

Promote and protect human rights

Eight characteristics were grouped under the concept of 'promoting and protecting human rights'. Recognising the value of the person was identified as a key characteristic of person-centred care when promoting and protecting their human rights.(29,111,112) In addition, demonstrating dignity and respect for the person was highlighted.(109,111,112) Examples of how this might look in practice for staff were, seeing and appreciating the person, listening to, and always asking for the person's preferences in all kinds of activities.(109) Finally, protecting the person from degrading treatment was addressed in relation to challenging behaviour, or when a person becomes agitated. The need for careful management of challenging behaviours to facilitate the use of least restrictive practices was highlighted, which may involve identifying triggers and the use of de-escalation techniques.(25,108,111,114,115)

The living environment

Five characteristics were grouped under the concept of 'the living environment'. The physical comfort of individuals was identified as contributing to person-centred care; the right to privacy for individuals, and choice in relation to how they are supported in their living environment, were regarded as important human rights.(32,33)

The opportunity to give feedback on service design and provision, and to be consulted about new service developments was identified as a key element of a human rights-based approach to care and was considered important by the people availing of respite services specifically.(25) Time and space to oneself was also considered a characteristic of person-centred care. For example, respite services were identified as providing personal and emotional space for the individual, and as a result seen to help maintain family relationships.(25)

Support to understand relevant information

Three characteristics were grouped under the concept of 'support to relevant understand information'. There is a need for accessible information to be available in relation to services, so that individuals can make their own decision about using these services.(32,33) Supporting individuals to understand their care records and care plans was regarded as important in terms of person-centred care and may facilitate autonomy and self-care.(24) Individual approaches to providing this support should be based on the person's needs and delivered in a way that the person can understand.(34,107) For example, information may be provided in the form of pictures, symbols and simple words to enhance knowledge and skills.(33)

Involving family and friends in line with the person's wishes

Six characteristics were grouped under the concept of 'involving family and friends in line with the person's wishes'. Characteristics were identified that related to the involvement of family members, also referred to as relatives, loved ones, informal networks, and friends. Family members were seen as crucial links between the person and formal care providers and as advocates in relation to the individualised care of a person.(24,115) It was noted that family involvement may improve person-centred care planning and support people to achieve their goals.(110) Challenges in relation to resistance or tensions between care staff and family members were identified, for example, where the wishes of the family members were different to the persons' own wishes. To ensure a human rights-based approach, family views can be considered but it was identified that it is important that the focus is on the wishes, needs and perceptions of the person themselves.(26,110)

Principle 2: Safety and wellbeing

There were 32 characteristics mapped to the principle of safety and wellbeing. It is important to note that the data mainly focused on wellbeing, with less focus on safety. These characteristics are listed in Appendix 5 and are grouped into six concepts:

1. social and family networks

2. person-centred approaches to planning
3. involvement of the person in their own care
4. improving wellbeing and quality of life
5. the physical environment
6. creating a homely and safe environment.

Social and family networks

Seven characteristics were grouped under the concept of 'social and family networks'. Social and family connections were identified as an important concept of person-centred care. Opportunities to meet new people, to meet old friends, or spend time with current friends and family were highlighted, as was the need to build and maintain relationships.(110) Activities such as watching television with others and going out with friends to the pub, cinema or to concerts were emphasised.(25) In contrast, group activities were not considered to have such a person-centred focus.(25) Community participation was recognised as a goal of person-centred care.(110) Examples of activities to achieve this included shopping trips, maintaining work in the community, and self-care (such as hairdresser, spa treatments).(110)

The allocation of time and places for people to engage with their social and family networks, was highlighted as important.(31) Staff can work with the person's family members, friends, and volunteers to get a full understanding of the person and support their changing needs effectively.(26) Involvement of family members provides emotional support to the person using the service.(32,33) By supporting engagement with the person's informal network, opportunities also arise for staff and the person's family and friends: to support each other, to solve problems together, to meet the persons changing needs, and to learn from each other.(115)

Person-centred approaches to planning

Six characteristics were grouped under the concept of 'person-centred approaches to planning' and described in several articles. It was described as a collaborative partnership between the person and staff to assess the person's support needs and align supports to their individual needs and desired personal outcomes.(116) Focus is placed on the person as a whole and their preferences, taking a strengths-based approach rather than focusing on deficits.(27) The findings show that person-centred planning allows people to actively participate in developing and implementing their individual support plan. It was reported that person-centred planning improves the life of people with disabilities, allows personal growth and development, and increases inclusion, empowering informed decision-making, autonomy and control over their own life.(27,34,107,116)

The beliefs and attitudes of the staff have an impact on person-centred planning, and as such it is important that staff undertake training to better understand their role and responsibilities. Training in areas such as active support, person-centred planning, support, decision-making, and positive behaviour support promote a cultural shift within services.(107,108,116)

The role of staff in person-centred planning was characterised as offering support while maintaining the person's autonomy. It was highlighted that, to support person-centred planning there is a need for staff to communicate meaningfully with the person, listen to and respect them, involve the person in an active way, and work in a flexible manner to adapt to the person's changing needs and wishes. In order to facilitate person-centred planning, staff can consider the person's wishes or desires; meet their changing support needs; celebrate the person's unique gifts and attributes; reflect on the person's accomplishments; and listen to person's hopes and dreams.(24,114,115)

Involvement of the person in their own care

Six characteristics were grouped under the concept of, 'involvement of the person in their own care'. Including and engaging the person in the development and implementation of their care and support were identified as important aspects of person-centred care.(24,32,33,112) In relation to children, there is a need for increased staff efforts to ensure children are involved in the development of their own support plans.(34) Allocating and setting time aside for individual conversations and to adapt methods of communication based on the child's needs is considered necessary to achieve increased levels of child involvement.(34)

The importance of taking a person's preferences into account to allow them to be in charge of their care was emphasised.(32,33) In relation to respite care, it was highlighted that staff can take a person's preferences into account by supporting opportunities for independence, and by enabling people to make their own choices. For example, ensuring people have opportunities to practise skills such as independent travel, money management, shopping, and personal care. It was noted that while using respite services, people may not be particularly concerned with personal goals, social roles or educational programmes associated with their day service, this is not their primary focus of respite care. However, skill development was viewed positively when it occurred organically during activities.(25)

Improving wellbeing and quality of life

Six characteristics were grouped under the concept of 'improving wellbeing and quality of life'. Fostering a positive environment and a positive social psychology within services was highlighted, as it supports wellbeing and quality of life.(29,111)

Similarly, the importance of healthful relationships, that place the person at the centre of care, was recognised as enabling the person to achieve maximum wellbeing and allowing them to flourish in all aspects of their life.(30) Service orientation, that is identifying and meeting the needs of people using services, was also deemed important, particularly in relation to people with challenging behaviours.(108) Person-centred interventions or procedures such as Positive Behavioural Support (PBS)[§§§§] can support staff to understand why a person has challenging behaviour and enable staff to better support the person. PBS is recognised as effective in improving the skills and quality of life of the person and those around them, while also keeping the person and those around them safe.(108)

In relation to respite services, it was highlighted that attending respite services should be an enjoyable experience, with a strong emphasis on fun and the opportunity to participate in new activities and visit new places.(25)

The physical environment

Four characteristics were grouped under the concept of 'the physical environment'. The role of the physical environment and the impact it can have on the lives of people with disabilities living in the service was highlighted. The evidence included that there is a need to ensure that buildings that house services are accessible to everyone using the service. This may include providing clear directions to and inside the building.

Services may need to alter and adapt physical environments, as necessary, to allow staff to work in a person-centred way.(32,33,113) For example, inadequate facilities such as bathrooms and showers can impact on the staff's ability to provide personal care in a safe and timely manner.(113) Services may also need to adapt physical environments to suit the needs of the person using the service, for example, adapting an ordinary house to make it suitable for a person with high levels of challenging behaviour, without making it look like an institutionalised setting.(108)

[§§§§] Positive Behavioural Support (PBS) is a person centred approach to problem behaviours and changing problematic environments. PBS aims to understand the reasons why a person has challenging behaviour, it changes the environment reducing the need for the person to have to use challenging behaviour, respects and includes the person, and is an ethical approach based on contemporary values and avoids the use of punishment.

Creating a homely and safe environment

Three characteristics were grouped under the concept of 'creating a homely and safe environment'. The need to create a homely and safe environment was highlighted; several characteristics related to the importance of the location, design and size of a service, and how residents are grouped within a service. The findings also highlighted that the location of a service should facilitate and enable easy access to local communities with amenities and allow residents to maintain and develop relationships with their families and the local community. Consideration should also be given to the design to ensure the best environment for people, creating a rich, homely, safe environment that is tailored to individual needs.(108)

In relation to size, careful consideration is required in relation to who and how many people live together within a particular service. Overcrowded, noisy environments can trigger challenging behaviours in residents, whereas small resident groupings with adequate staff ratios, allows flexible targeted allocation of support staff to residents. Small resident groupings can have beneficial effects on the people living in the service, especially in relation to their interactions and participation within the service. The findings show that to ensure a person-centred approach, residential services should be provided in a range of sizes, including single person services.(25,108)

Finally, in relation to resident groupings in respite services, it was recognised that people may have strong preferences for who they would like to be grouped with, for example with friends or people they know and like. It was highlighted that people may wish to be involved in the planning of potential groupings, meet with other residents in advance of their respite stay or attend respite with people of the same gender. It was indicated that female residents may feel uncomfortable with male residents in the same service and may have more shared interests with other women.(25)

Principle 3: Responsiveness

There were 50 characteristics mapped to the principle of responsiveness. These characteristics are listed in Appendix 5 and are grouped into six concepts:

1. positive relationships with staff
2. communication
3. an individualised approach to care and support
4. coordination of care and transitions
5. person-centred approaches to care
6. adjusting care and support to peoples' needs.

Positive relationships with staff

Ten characteristics were grouped under the concept of 'positive relationships with staff'. Positive relationships between staff and those who use the service were considered a key element to responsiveness and fundamental to person-centred care.(25,115) These relationships were characterised as warm, caring and committed.(35) Familiarity was identified as an important factor for person-centred care, that is familiar staff know the person who they are supporting, and the person knows the staff.(110) To build positive relationships and connect, it is important that staff are honest, sincere, polite, kind and that they listen and show care and respect.(24,25,115) Relationship building can be supported by staff ensuring they are informed about the person and their life and by being attentive to the person's needs. Staff can be attentive to people's needs and preferences by interpreting the needs of the person and responding appropriately.(35) Other important characteristics that support positive relationships included the provision of emotional support and ensuring there are 'momentary fun interactions' between staff and those using the service.(24,25,32,33,107) 'Momentary fun interactions' was described as staff engaging directly with people who were more attuned to sensory forms of engagement than words.(35)

Communication

Nine characteristics were grouped under the concept of 'communication'. Challenges with communication are not uncommon and therefore staff need to work with the individual and their family and friends (as appropriate) to ensure the person is supported to make as many choices as possible using whatever means are available to them, so that they remain in control.(28) Communication is a human right and therefore it is essential that staff learn each person's preferred communication methods to ensure they can be heard.(24) Staff can focus on the person's perspective to better understand the needs and behaviour of the person.(115) They can do this by gaining an understanding of the person's preferences, likes and dislikes and their ambitions, hopes and dreams for the future.(24,111,112,114) Staff can ask questions to gain a better understanding of the person, for example 'How can we make changes to make this person feel better, help this person feel better, or learn more about them?'.(24)

An individualised approach to care and support

Nine characteristics were grouped under the concept of 'an individualised approach to care'. An individualised approach to care recognises the uniqueness of the person and their unique gifts, attributes and accomplishments.(24,29,111) It is important that staff take the time to focus on and understand the world from the perspective of the person, to ensure they understand who the person is and how they view the world.(29,31,111) To respect the individual in a group setting, it is important to support them to have choice and control. In practice this could mean asking a question such as 'what type of fruit would you like?' in an individually adapted way for each person.(109)

Coordination of care and transitions

Nine characteristics were grouped under the concept of 'coordination of care and transitions'. To ensure person-centred care, it is essential that care is coordinated within and between services.(32,33) Professionals should be informed about those they are caring for and should work as a team with other professionals to ensure coordinated care. A person should only be required to explain their situation once and should not have the burden of giving the same information several times.(32,33) If a person is moving between services, their information should also be transferred, and they should be made aware about where they are going and what care and support they should expect to receive.(32,33) If a person is being discharged from a service (for example from hospital or respite care) they should be provided with skilled advice about the care and support needed following discharge.(32,33)

To support coordination and collaboration within and between teams, a culture of safety and trust is required within the team. This climate of safety within the team empowers staff to work in the best interests of the people who use the service.(31,115)

Person-centred approaches to care

Seven characteristics were grouped under the concept of 'person-centred approach to care'. To enable staff to provide more person-centred care, a shift is required, from a task-oriented way of working to a person-centred way of working.(29) To support this shift, it is essential that staff pay attention to the person and their experience, including any anxiety they may be feeling about their situation.(32,33) The person and their needs should take priority over staff needs and tasks.(35)

The characteristic of 'narrative competence' is described as a person-centred approach that enabled staff to identify a person's experiences, capabilities and needs. Narrative competence is the ability of staff to verbalise or narrate the needs of a person. This is particularly important where cognitive and communicative challenges make it difficult for a person to speak up for themselves.(26)

Another characteristic identified was active support. Active support was described as a person-centred practice that enables people to engage in meaningful activities and social interactions. Staff use everyday opportunities to engage a person and support their participation by providing the right type and amount of assistance, and choice in terms of what they do and when, while tailoring communication to the person and having warm interactions.(107)

The need for training was identified, including implementing a service wide training programme on the fundamental principles of a person-centred approach and its practical application.(110)

Adjusting care and support to peoples' needs

Six characteristics were grouped under the concept of 'adjusting care and support to peoples' needs'. The characteristics of flexibility and continually adjusting to the persons' current needs outlined how staff can use their time flexibly and change plans to organise their time around the current needs of the resident rather than focusing on the completion of tasks, rigid adherence to a daily routine, or their own needs.(31,35,115) Other characteristics highlighted the need for staff to focus on physical comfort; pay attention to pain management; continuously and actively search for the person's needs and possibilities; and take people's preferences into account to ensure their comfort.(32,33,111)

Principle 4: Governance and accountability

There were 13 characteristics mapped to the principle of governance and accountability. These characteristics are listed in Appendix 5 and are grouped into five concepts:

1. access and availability of care and support
2. coordination of care and use of information
3. ensuring appropriate grouping of residents
4. person-centred principles at an organisational level
5. safe and trusting team culture.

Access and availability of care and support

Three characteristics were grouped under the concept of 'access and availability of care and support'. The need to ensure that the physical supports and the buildings that house services are accessible and available to everyone was highlighted.(32,33) People should also be able to easily schedule and manage appointments.(32,33) The characteristic of available and flexible supports refers to the need for people to access services at the time when they need it.(25) The issue of equity in relation to service provision was also raised, for example, access to services should not be limited based on where someone lives.(25,32,33)

Coordination of care and use of information

Three characteristics were grouped under the concept 'coordination of care and use of information'. Coordination of care is an important concept related to governance and accountability, as services have a responsibility to ensure coordinated and safe care and support to make sure that people do not experience any gaps in their care and support. To ensure this, care must be well coordinated among staff at an organisational level and staff need to work as a team in delivering care. The appropriate use of information supports this coordination of care, and it is important that when a person is transferred, either within a service or to another service, that the person's information is transferred also.(32,33)

Ensuring appropriate grouping of residents

Three characteristics were grouped under the concept of 'ensuring appropriate grouping of residents'. It is important to plan and manage services to ensure people using the services are grouped in an appropriate and safe way.(25) It was noted that people often have a preference to be grouped with the same gender or people of similar age, as they feel more comfortable and have more shared interests.(25) Services also need to ensure appropriate groupings for those with behaviour support needs and ensure that staff have the skills and experience to manage this.(111)

Person-centred principles at an organisational level

Two characteristics were grouped under the concept of 'Person-centred principles at an organisational level'. This concept relates to the need to adopt or implement the principles of person-centred care at an organisational level to support cultural transformation within services.(24,108) This may include implementing a holistic approach to person-centred planning within the service.(24) This concept also relates to the need to have person-centred procedures in place that are well understood by staff and are implemented in person-centred ways.(108)

Safe and trusting team culture

Two characteristics were grouped under the concept of 'safe and trusting team culture'. The importance of a team culture that is based on safety and trust was highlighted. This was described as a culture in which staff are open and honest with each other based on safety and trust.(115) In such a culture, teams develop a bond in which they experience this safety and trust, as well as genuine interest in and attention to the well-being of all colleagues.(31) Teams with this positive culture often 'speak the same language' and are 'on the same page'; there is a climate of safety on the team; the team works in collaboration and feel empowered.

4.4 Summary

This scoping review aimed to identify peer-reviewed literature that described definitions and or characteristics of person-centred care for people with disabilities living in residential services, without particular reference to the methodological quality of the sources of evidence. The search strategy followed the JBI methodology for scoping reviews, and was limited to articles published in or after 2013 (since the last standards were published).

From a total of 958 articles, 23 articles were included in this scoping review. They presented data from the perspectives of people with disabilities, staff, family members, policymakers, and experts in the field of disability, behaviour, frailty and ageing. All of the articles reported on people with intellectual disabilities. Of the 12 articles that reported the age of the people with disabilities, one article reported on children between the age of six and 16, all others reported on adults only.

4.4.1 Summary of key lessons for Ireland

This scoping review has provided an understanding of how person-centred care is defined and characterised in residential services for people with disabilities.

Twenty definitions of person-centred care were identified in the review, highlighting that person-centred care:

- places the person at the centre of their care
- focuses on and respects the person's needs and preferences
- supports the person to make decisions, meaningful choices, participate in their own care and engage in society
- involves a partnership approach with staff, family and friends, with the person at the centre
- requires staff that are respectful, flexible, attentive, sensitive, motivated, and effective.

The review provided key lessons for Ireland in relation to the four principles of person-centred care that underpin all national standards developed by HIQA.

Principle 1: A human-rights based approach

The following concepts and characteristics were identified in relation to a human-rights based approach in residential services for people with disabilities:

- **Autonomy** — Autonomy was described using terms such as empowerment, inclusion, independence, choice and control. A person should have autonomy in relation to where they live, and who they want as their advocate. There is a need for staff to support people to have a voice, and to listen to and act on their wishes in relation to their care.
- **Promoting and protecting human rights** — The value of the person should be recognised, demonstrating dignity and respect. Careful

management of challenging behaviour is required to facilitate the use of least restrictive practices.

- **The living environment** — People have the right to safety and privacy, and should have a say in the design, provision and development of the residential services they use.
- **Support to understand relevant information** — There is a need for accessible information to be provided to people to support them to voice their opinions and to understand their care records and care plans.
- **Involving family and friends in line with the person's wishes** — Family members were seen as crucial links between the person and formal care providers, and as advocates in relation to the individualised care of a person.

Principle 2: Safety and Wellbeing
In relation to safety and wellbeing in residential services for people with disabilities, the following concepts and characteristics were identified:

- **Social and family networks** — There is a need to support people to engage with their social and family networks, and for residential services to provide opportunities for them to do so. Staff, family and friends can also support and learn from each other.
- **Person-centred approaches to planning** — Person-centred planning is a collaborative partnership between the person and the service provider which allows people to actively participate in developing and implementing their individual support plan. It increases inclusion and empowers informed decision-making and autonomy.
- **Involvement of the person in their own care** — There is a need to include and engage the person in the development and implementation of their care and support, and to take their preferences into account. Children require particular support in relation to the development and implementation of their support plans.
- **Improving wellbeing and quality of life** — The person should be placed at the centre of care to ensure their needs can be identified and met. Fostering a positive environment within services with opportunities for fun and new activities was highlighted.
- **The physical environment** — The buildings that house services should be accessible to everyone using the service, and adapted as necessary to allow staff to work in a person-centred way.
- **Creating a homely and safe environment** — The location, design and size of a service, and how residents are grouped within a service are important. Services should provide a safe, inclusive and homely living environment that meet people's individual physical and emotional needs.

Principle 3: Responsiveness
In relation to responsiveness in residential services for people with disabilities, the following concepts and characteristics were identified:

- **Positive relationships with staff** — It is important for staff to foster positive, warm, caring and committed relationships with people using the service. Staff should make efforts to be informed about the person and their life, be attentive to their needs, and provide emotional support and fun interactions.
- **Communication** — There is a need for staff to learn each person's preferred communication methods to ensure their voice can be heard, and to understand the person's preferences, and their ambitions, hopes and dreams for the future.
- **An individualised approach to care and support** — The uniqueness of the person and their individual gifts, attributes and accomplishments should be recognised. Staff have a responsibility to support them to have choice and control.
- **Coordination of care and transitions** — There is a need for coordination of care within and between services, this can be facilitated by a culture of safety and trust within teams and information sharing. A person should only be required to explain their situation once.
- **Person-centred approaches to care** — There is a need for staff to shift from a task-oriented way of working to a person-centred way of working, the person and their needs should take priority over staff needs and tasks. Approaches such as narrative competence and active support enable staff to identify a person's experiences, capabilities and needs, and enables the person to engage in meaningful activities and social interactions.
- **Adjusting care and support to peoples' needs** — There is a need for staff to be flexible, organise their time, and continually adjust to the persons' current needs, rather than focusing on the completion of tasks, rigid adherence to a daily routine, or their own needs.

Principle 4: Governance and accountability
In relation to governance and accountability in residential services for people with disabilities, the following concepts and characteristics were identified:

- **Access and availability of care and support** — People should have equitable access to services, and the buildings that house services, when they need it.
- **Coordination of care and use of information** — To ensure that people do not experience any gaps in care and support, coordinated and safe care and support is required. This includes appropriate use and sharing of information about the person. Care should be coordinated at an organisational level and staff need to be supported to work as a team in delivering care.
- **Ensuring appropriate groupings of residents** — It is important to ensure safe and appropriate grouping of people with disabilities within residential services. For those with behaviour support needs, staff should have the skills and experience to manage this.
- **Person-centred principles at an organisational level** — Services should adopt or implement the principles of person-centred care at an

organisational level, with procedures in place that are well understood by staff.

- **Safe and trusting team culture** — It is important to build a team culture that is based on safety and trust, in which staff are open and honest with each other and there is a genuine interest in, and attention to, the wellbeing of all colleagues.

5. Discussion, Conclusion and Next Steps

This evidence review to inform an update to the *National Standards for Residential Services for Children and Adults with Disabilities* sets out the evidence that was reviewed and includes three elements:

- an overview of regulation of residential services for children and adults with disabilities in Ireland
- a review of international standards and related documents for residential services for children and adults with disabilities
- scoping review of peer-reviewed literature to identify the characteristics of person-centred care in residential services for children and adults with disabilities.

In Ireland, progress has been made to improve the safety and quality of designated centres for people with disabilities since the publication of the *National Standards for Residential Services for Children and Adults with Disabilities* in 2013. Changes in the sector include the introduction of regulation of residential services for people with disabilities in 2013, and the introduction of new legislation.

In 2018, Ireland signed and ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), and in 2023 the Assisted Decision-Making (Capacity) Act 2015 (ADMA) came into effect. However, the sector continues to face significant challenges. HIQA's report, *10 Years of Regulating Designated Centres for People with Disabilities*, recognised that there is currently no overarching social care policy or legislation in Ireland to outline how people, including people with disabilities, should be cared for and supported into the future.(3) The report also highlighted that the Health Act 2007 and associated regulations are not sufficiently underpinned by a human rights-based approach to care, and there is a need for specific safeguarding legislation to ensure all residents are protected from harm.(3) The report indicated that there is currently insufficient capacity in disability services to enable planning for emergency action for children or adults who are in crisis circumstances.(3) Since 2013, there has been a move away from congregated settings to smaller settings within the community, however this process is still ongoing and, in 2023, 25% of people with disabilities living in designated centres in Ireland were still living in congregated settings.

This section highlights key findings from the overall review, mapped to the four principles of person-centred care that underpin all national standards developed by HIQA. It also includes a section on residential services for children with disabilities and key considerations that relate to children specifically.

Principle 1: A human-rights based approach

In Ireland, the current *National Standards for Residential Services for Children and Adults with Disabilities* address a human rights-based approach to care, however the focus on this is limited. A key finding of this review is that there is now a far greater emphasis on a human rights-based approach to care in services. The key characteristics outlined in this evidence review, which relate to a human rights-based approach, should all form part of the everyday practices within residential services for people with disabilities, and be considered in any update to the national standards.

In line with the UNCRPD, there is consensus in Ireland and internationally, that people with disabilities have the same human rights as everyone else. For example, in Australia*,* guidelines state that each person's access to specialist accommodation should be consistent with their legal and human rights, and they should be supported to exercise informed choice and control.(7) In Northern Ireland, standards state that residents' individual and human rights should be safeguarded and actively promoted within the context of services delivered by the care home.(8)

Following to the publication of the standards in 2013, HIQA has worked to promote a human rights-based approach in residential services, and has supported providers to embed human rights-based principles into their everyday practices. Although the existing *National Standards for Residential Services for Children and Adults with Disabilities* in Ireland refer to the human rights of individuals, a greater focus on a human rights-based approach to care would strengthen the standards.

The evidence emphasised that there should be a focus on the person with a disability, placing them at the centre of everything. The review of international standards and related documents, as well as the findings from the scoping review, identified several characteristics that should be applied in practice to ensure person-centred care. For example, in Northern Ireland the uniqueness and intrinsic value of individual residents, and their right to be treated with respect was acknowledged. In Scotland, being given a voice, being listened to, and being involved in decisions which affect the person's wellbeing, was identified.(8,17) For people with disabilities in Sweden, a national goal has been set to achieve equal living conditions and full participation in society. Also in Sweden, there is an active focus on identifying shortcomings and obstacles that make it more difficult for people with disabilities to participate on the same terms as the rest of the population.(11)

The evidence from the scoping review identified that disability services should promote and protect the human rights of people with disabilities, including demonstrating dignity and respect, and listening to and asking for their preferences.(29,32,33) Key findings in this review highlighted that people with disabilities should have autonomy in relation to where and how they live, and the care and support they receive.(32,33,115) They should be supported to have a voice, and to understand and have accessible information about their care.(32,33)

Additional findings showed that people with disabilities should be consulted and given the opportunity to give feedback on service design and provision, and provided with safe living environments that are consistent with their legal and human rights.(25) Family and friends can advocate on their behalf and should be involved, in line with the wishes of the person, to improve person-centred care planning, and support them to achieve their goals.(32,33,110,115)

This review identified that there should be careful management of challenging behaviour, and that restrictive practices must be reduced or eliminated as much as possible, in accordance with regulations in Ireland, and the UNCRPD.(3,9,24,107,115,117) Service providers, management and staff should be aware of the impact of restrictive practices on residents, and training in relation to de-escalation techniques and use of least restrictive practices is needed, as appropriate.(107,111)

Principle 2: Safety and wellbeing

This evidence review has highlighted key characteristics relating to safety and wellbeing that can be considered in any future update of the national standards: especially those relating to safeguarding, person-centred planning and resident groupings. Importantly, where institutionalised practices are still in place in some services in Ireland, the move away from congregated settings provides new opportunities for the concepts and characteristics that relate to safety and wellbeing to be considered.

The evidence from all three elements of this review emphasised the importance of supporting the physical and mental health of people with disabilities in residential services, including the right to feel safe and secure in a homely and accessible environment, with safeguarding measures in place that prevent harm, and that respond quickly to harm, abuse and neglect when it does occur. For example, in Northern Ireland, the *Minimum Standards for Children's Homes* stated that children and young people should feel safe in all aspects of their care and can expect that every service will employ a zero tolerance of abuse, harm and neglect, and will work to the highest standards of safeguarding practice.(16)

The scoping review highlighted characteristics that related to the importance of the location, design and size of a service; homely and safe living environments that meet people's individual physical and emotional needs; and that are close to local communities.(25,108)

The provision of timely assessments of risk and need was identified as an important area. In addition, the need for services and supports that are tailored to the individual's needs, with a focus on wellbeing and quality of life was also identified. For example, local authorities in England are expected to be mindful of the capacity, capability, timeliness, continuity, reliability and flexibility of services delivered to support the wellbeing of those using services.(18)

The scoping review identified that residential services need to support and provide opportunities for people to engage with their social and family networks, to foster community participation and inclusion. Examples of community activities include eating out in restaurants, attending music or sporting events, shopping trips and self-care (such as hairdresser, spa treatments).(24,25,31,110)

Another important characteristic was person-centred planning; this is a collaborative partnership between the person and the service provider. This allows the person to actively participate in developing and implementing their own support plan. Collaboration takes the person's preferences into account, and increases their inclusion, empowerment and autonomy.(24,30,110,113) However, person-centred planning relies heavily on the beliefs and attitudes of the staff involved. For this reason, it is important to consider staff training in areas such as active support, person-centred planning, decision-making, and positive behaviour support, to promote a cultural shift within services. Children require particular support to enable them to engage in person-centred planning in a meaningful way.(34)

Evidence from the scoping review also highlighted that the way residents are grouped within a service is an important consideration in relation to safety and wellbeing. Small resident groupings can have beneficial effects on the residents, especially those with additional behavioural needs, and in relation to their interactions and participation within the service.(25,108) The need to transition residents from large, campus-based or congregated settings into smaller living arrangements in the community, was identified as a key aspect of safety and wellbeing, in all three elements of the review.

In relation to respite care, the scoping review identified that it is important to support opportunities for independence and to enable people to make their own choices; that attending should be an enjoyable experience, with a strong emphasis on fun and the opportunity to participate in new activities and visit new places; that while using respite services, personal goals or educational programmes associated with their day service was not the primary focus of respite care.(25)

Principle 3: Responsiveness

The *National Standards for Residential Services for Children and Adults with Disabilities* include standards under the theme 'responsive workforce'. A workforce who are well trained and work in a person-centred way, with good communication between staff and residents, and continuity of care and smooth transitions within and between services for residents, are important characteristics of responsiveness for consideration in any update to the national standards.

The evidence from all three elements of the review identified that a responsive workforce, who are skilled, experienced and trained, who are clear about their roles and responsibilities, and have the resources to carry out their duties, was essential to providing responsive person-centred care. For example, a Canadian standard highlights the importance of fostering a healthy and competent workforce and promoting a culture of quality improvement and learning across long-term care homes.(22) In Northern Ireland, all care staff are expected to have appropriate experience, qualifications, skills, values and competence, and need to be supported in their role to meet the assessed needs (including any needs related to disability) when caring for children in care homes.(16)

The scoping review additionally described the need for staff to shift from a task-oriented way of working to a person-centred way of working, where the person and their needs take priority over staff needs and tasks.(29,35) The national evidence demonstrated that the provision of care in Ireland has evolved since 2013; the majority of providers now embrace a more social model of care, in which care is delivered in a more person-centred manner.(3)

The evidence identified additional characteristics that work together to support responsive, person-centred care. These are communication, trust, integration, continuity of care, and cooperative partnerships between service users, service providers and families.(25,32,33,116) When present together, these characteristics ensure that the person in the residential setting has confidence in the care being provided, in the level and quality of information being shared with others, and in the coordination and continuity of their care. In relation to communication specifically, the review highlighted that staff must learn each person's preferred communication methods to ensure that they can respond to their needs and wishes, and develop trusting relationships with them, and with the teams they work with.(24,31,107) Good lines of communication within organisations allow responsive action when required.(31,115)

Transitioning within and between services was addressed in all three elements of the review. People with disabilities, and children, were identified in the review of international standards and related documents as needing more support when transitioning between services.(36) The review of international standards and related documents, as well as the scoping review, provided characteristics of planned and supported transitions.(7,12,13,18,20,36-38) Smooth transitions are facilitated by a culture of safety and trust within teams, and appropriate information sharing.(31,33,37,38) In Scotland, the *Looked After Children (Scotland) Regulations 2009* outline the child's journey into and through all care settings, and set out the principles that should be followed, and the *Support and Assistance of Young People Leaving Care (Scotland) Regulations 2003* outline the processes that local authorities must follow when a young person is leaving care.(37,38) It is important to involve the person with a disability at all stages, to assess the appropriateness of the new setting, to provide detailed written information to the care setting, develop pathway assessments and pathway plans when transitions are planned, and to keep all relevant stakeholders informed.(25,32,33,37,38)

Principle 4: Governance and accountability

In Ireland, the current *National Standards for Residential Services for Children and Adults with Disabilities* address governance and accountability under the theme of 'leadership, governance and management' in relation to the management arrangements in place for the delivery of services, describing it as directing and managing activities using good business practices, objectivity, accountability and integrity, at individual, team and service levels. The concepts and characteristics identified under governance and accountability in this review provide more clarity on what an accountable service looks like and should be considered in any update to the standards.

The evidence from both the overview of regulation in Ireland and the review of international standards, identified governance and accountability as being important elements of person-centred care. The *National Standards for Residential Services for Children and Adults with Disabilities* address governance and accountability under the theme of 'leadership, governance and management', describing it as directing and managing activities using good business practices, objectivity, accountability and integrity, at individual, team and service levels, and includes decision-making, risk management and meeting strategic, statutory and financial obligations. Since the publication of the standards in 2013, many providers in Ireland have undertaken actions to improve the effectiveness of their governance arrangements.

Strategy, governance, management, responsibility, culture, information management, learning, compliance, and regulation were identified as key elements to support the implementation of standards. For example, in Australia, effective tenancy management was identified as vital to supporting residents to exercise choice and control.(7)

The need to adopt or implement the principles of person-centred care at an organisational level was also identified as a requirement for systems and cultural transformation within services to take place.(24,107,116) An example of good practice identified is the implementation of a holistic approach to person-centred planning within the service that is understood and implemented by all staff.(108) There is a need to ensure that people with disabilities have equitable access to services, and to the buildings that house services, when they need it.(32,33) It is important to ensure person-centred coordination of care, at an organisational level, with procedures in place that are well understood by staff, so that people do not experience any gaps in care and support.(32,33) The evidence highlighted the need for the development of governance strategies, at both a country and organisation level, to support the regulation and implementation of standards.(7,8,22) To support system improvement, organisational culture was highlighted as an important characteristic.(24,108) There needs to be a culture of information sharing to support coordinated care, and a culture that supports continuous learning among staff. The review highlighted the importance of building a team culture that is based on safety and trust, a just culture that prioritises system improvement over blame and judgement, where staff are open and honest with each other, and there is a genuine interest in and attention to the wellbeing of all colleagues.(7,8,22,31,115)

The review of international standards and related documents, as well as the scoping review, also identified that it is important to ensure safe and appropriate grouping of people with disabilities within residential services. For those with behaviour support needs, staff should have the skills, experience and training to manage this.(7,25,108,111,114,115)

Residential services for children with disabilities

Overall, there was limited data relating specifically to children with disabilities in residential care. On a national level the regulations and the 10-year overview report do not differentiate between children and adults. Four overarching documents in the international review, relating to residential care and disability care generally, applied to children and or young people only.(16,17,19,20) Eleven documents related to both children and adults. For example, in Scotland the *Health and Social Care Standards; My Support, my life* (2017) states that the standards are for everyone and that, irrespective of age or ability, all are entitled to the same high-quality care and support.(10) Only one article in the scoping review reported on children between the age of six and 16, all others reported on adults only.(34)

While the findings from the report suggest that standards can apply equally to both children and adults, it has highlighted several key areas for consideration in relation to children specifically:

- The aim internationally is to provide support so that as many children as possible live at home, in foster care, or in family-like environments, where they can maintain family and community supports.(16,17,19,20) In New Zealand, for example, one of the stated outcomes of disability support services strategy was to begin early by investing in families to support them to be aspirational for their child with a disability and to build community and natural supports.(14) In England and Scotland, while still focused on a residential placement, all local options are explored before using long-distance placements, and the care system aims to have quicker decisions made about where the children will live permanently.(19,20)
- Where children with disabilities are in residential care, there is a need to have staff that are skilled and trained in engaging with children to ensure they can be involved in their own care and person-centred care planning. Allocation of time for individual conversations, and adaptation of the methods of communication are required.(34)
- Children were also identified as needing more support when transitioning in and between services and the international and scoping reviews provided some characteristics of planned and supported transitions.(7,12,13,18,20,36-38)

Conclusion

This evidence review has highlighted that there are key areas of change, on a national level, since the publication of the *National Standards for Residential Services for Children and Adults with Disabilities* in 2013*.*(1) The review of standards and related international documents internationally identified key areas that should be considered in any update to the standards. The peer-reviewed literature provided additional up-to-date evidence and highlighted important characteristics of person-centred care for people with disabilities living in residential service.

Next Steps

This evidence review is one part of the HIQA standards development process. The development and updating of national standards also includes engagement with stakeholders through an advisory group, focus groups and public consultation. The outcomes from this evidence review, and the stakeholder engagement process, will inform any future updating of these standards.

Strengths and limitations

There are several limitations to this study which should be noted.

The overview of regulation of residential services was largely limited to examination of a single report *'10 Years of Regulating Designated Centres for People with*

Disabilities'. While inclusion of additional sources may have been helpful, it should be noted that this report provides a comprehensive and singular insight into developments in the sector over time.

The international review provided a detailed overview of relevant standards internationally. A comparative analysis may have been useful; however, it was beyond the scope of this review.

Although it should be noted that five separate databases were accessed for the scoping review, it is possible that additional relevant studies may have been indexed on databases other than the ones searched. It is also possible that relevant studies may not have been captured by the search strategies. We did not assess the quality of peer-reviewed studies, as this is not a requirement of scoping reviews.

Overall strengths of the review include the triangulation of distinct sources to provide a comprehensive and up-to-date overview of the landscape, while the methods used were systematic and robust. Registration of the scoping review search strategy and protocol, mean the methods are transparent and reproducible.

References

1. Health Information and Quality Authority. National standards for residential services for children and adults with disabilities. 2013. Accessed on: 10 September 2024. Available from: https://www.hiqa.ie/reports-and-publications/standard/national-standards-residential-services-children-and-adults.
2. Health Information and Quality Authority. Regulation handbook: A guide for providers and staff of designated centres Version 2.2. 2024. Accessed on: 14 January 2024. Available from: https://www.hiqa.ie/sites/default/files/2019-10/Regulation-Handbook.pdf.
3. Health Information and Quality Authority. 10 Years of Regulating Designated Centres for People with Disabilities. 2024. Accessed on: 24 December 2024. Available from: https://www.hiqa.ie/sites/default/files/2024-11/DCD-10-year-overview-report.pdf.
4. United Nations. Convention On The Rights Of Persons With Disabilities 2006. Accessed on: 13 December 2023. Available from: https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf.
5. Assisted Decision-Making (Capacity) Act 2015, Ireland. 2015. Accessed on: 10 December 2021. Available from: https://www.irishstatutebook.ie/eli/2015/act/64/enacted/en/html.
6. Health Service Executive. Time to Move on from Congregated Settings: A Strategy for Community Inclusion 2011. Accessed on: 10 October 2024. Available from: https://www.hse.ie/eng/services/list/4/disability/congregatedsettings/time-to-move-on-from-congregated-settings-%E2%80%93-a-strategy-for-community-inclusion.pdf.
7. National Disability Insurance Scheme Quality and Safeguards Commission. National Disability Insurance Scheme (Quality Indicators for NDIS Practice Standards) Guidelines 2018. 2024. Accessed on: 20 September 2024. Available from: https://www.legislation.gov.au/F2018N00041/latest/text.
8. Department of Health, Social Services and Public Safety. Residential Care Homes Minimum Standards. 2021. Accessed on: 19 September 2024. Available from: https://www.rqia.org.uk/RQIA/media/RQIA/Resources/Standards/care-standards-residential-care-homes_2021.pdf.
9. Ministry of Health. Ngā paerewa Health and disability services standard. 2021. Accessed on: 16 September 2024. Available from: https://www.standards.govt.nz/shop/nzs-81342021.
10. Scottish Government. Health and Social Care Standards; My Support, my life. 2017. Accessed on: 2024 September 19. Available from: https://www.gov.scot/binaries/content/documents/govscot/publications/advice-and-guidance/2017/06/health-social-care-standards-support-life/documents/health-social-care-standards-support-life/health-social-care-standards-support-life/govscot%3Adocument/health-social-care-standards-support-life.pdf.
11. Socialstyrelsen; the national board of health and welfare. Swedish disability policy – service and care for people with functional impairments. 2009. Accessed on: 20 September 2024. Available from:

https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2009-126-188_2009126188.pdf.
12. Scottish Government. National Care Standards: Care homes for people with learning disabilities. 2011. Accessed on: 23 October 2024. Available from: https://www.gov.scot/publications/national-care-standards-care-homes-people-learning-disabilities/pages/1/.
13. Scottish Government. National care standards - care homes for people with physical and sensory impairment. 2011. Accessed on: 23 October 2024. Available from: https://www.gov.scot/publications/national-care-standards-care-homes-people-physical-sensory-impairment/.
14. Ministry of Health. Where I Live; How I Live, Disability Support Services Community Residential Support Services Strategy, 2018 to 2020. 2018. Accessed on: 23 September 2024. Available from: https://www.health.govt.nz/system/files/2018-03/dss-community-residential-support-services-strategy-2018-2020-mar18.pdf.
15. Minister of Labour, Family and Social Affairs. Rules on standards and norms for social protection services. 2010. Accessed on: 24 October 2024. Available from: https://www.uradni-list.si/glasilo-uradni-list-rs/vsebina/2010-01-2321.
16. Department of Health, Social Services and Public Safety. Minimum Standards for Children's Homes. 2023. Accessed on: 19 September 2024. Available from: https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/care-standards-childrens-homes-full-version.pdf.
17. Scottish Government. Children and Young People (Scotland) Act 2014: Statutory Guidance on Part 9: Corporate Parenting. 2015. Accessed on: 1 November 2024. Available from: https://www.gov.scot/binaries/content/documents/govscot/publications/advice-and-guidance/2015/08/statutory-guidance-part-9-corporate-parenting-children-young-people-scotland/documents/00483676-pdf/00483676-pdf/govscot%3Adocument/00483676.pdf.
18. Department of Health and Social Care. Care and support statutory guidance. 2024. Accessed on: 26 September 2024. Available from: https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance#general-responsibilities-and-universal-services.
19. National Institute for Health and Care Excellence. Disabled children and young people up to 25 with severe complex needs: integrated service delivery and organisation across health, social care and education. 2022. Accessed on: 2024 September 19. Available from: https://www.nice.org.uk/guidance/ng213/resources/disabled-children-and-young-people-up-to-25-with-severe-complex-needs-integrated-service-delivery-and-organisation-across-health-social-care-and-education-pdf-66143773521349.
20. Scottish Government. Getting it right for looked after children and young people strategy. 2015. Accessed on: 23 October 2024. Available from: https://www.gov.scot/publications/getting-right-looked-children-young-people-strategy/.
21. National Institute for Health and Care Excellence. Care and support of people growing older with learning disabilities. 2018. Accessed on: 20 September 2024.

Available from: https://www.nice.org.uk/guidance/ng96/resources/care-and-support-of-people-growing-older-with-learning-disabilities-pdf-1837758519493.

22. Health Standards Organization. CAN/HSO 21001:2023 (E) Long-Term Care Services. 2023. Accessed on: 25 September 2024. Available from: https://healthstandards.org/standard/long-term-care-services-can-hso21001-2023-e/.

23. Welsh Government. The Regulation and Inspection of Social Care (Wales) Act 2016; Statutory Guidance. 2024. Accessed on: 25 October 2024. Available from: https://www.gov.wales/sites/default/files/publications/2024-03/guidance-for-care-home-and-domiciliary-suppliers-2024.pdf.

24. Blessing, C., Brendli Brown, K.R., Pandey, T., Simmons, H., O'Brien, J. Changing practices, procedures, and perceptions: A multi-year person-centered planning initiative in group homes for residents with intellectual and developmental disabilities. Journal of Intellectual Disabilities. 2025.

25. Gadd, T. Person-centred respite supports: The perspectives of adults with intellectual disabilities in Ireland. British Journal of Learning Disabilities. 2020;48(4):281-90.

26. Gjermestad, A. Narrative competence in caring encounters with persons with profound intellectual and multiple disabilities. International Practice Development Journal. 2017;7:1-11.

27. Ouellette-Kuntz, H., Martin, L., Burke, E., McCallion, P., McCarron, M., McGlinchey, E., et al. How best to support individuals with IDD as they become frail: Development of a consensus statement. J Appl Res Intellect Disabil. 2019;32(1):35-42.

28. Özdemir, A., Hall, R., Lovell, A., Ellahi, B. Nutrition knowledge and influence on diet in the carer–client relationship in residential care settings for people with intellectual disabilities. Nutrition Bulletin. 2023;48(1):74-90.

29. Schaap, F.D., Dijkstra, G.J., Reijneveld, S.A., Finnema, E.J. Use of dementia care mapping in the care for older people with intellectual disabilities: A mixed-method study. Journal of applied research in intellectual disabilities : JARID. 2021;34(1):149-63.

30. Jackman-Galvin, V., Partridge, M. Relationships and power: An exploration of person-centredness in an intellectual disability service in Ireland. Health & Social Care in the Community. 2022;30(6):e6294-e302.

31. Thalen, M., van Oorsouw, W.M.W.J., Volkers, K.M., Frielink, N., Embregts, P.J.C.M. Providing person-centred care to older people with intellectual disabilities during the COVID-19 pandemic: experiences of direct support workers. International Journal of Developmental Disabilities. 2023;69(5):775-81.

32. Cramm, J.M., Nieboer, A.P. Validation of an instrument to assess informal caregivers' perceptions about the delivery of patient-centred care to people with intellectual disabilities in residential settings. BMC Health Services Research. 2019;19(1):518.

33. Cramm, J.M., Nieboer, A.P. Validation of an instrument to assess the delivery of patient-centred care to people with intellectual disabilities as perceived by professionals. BMC Health Services Research. 2017;17(1):472.

34. Wallin, P., Petersson, C., Josefsson, K.A., Nordin, A. Enhancing staff capacity to support children with intellectual disability receiving residential services: A realist

evaluation of an improvement program. Journal of Policy and Practice in Intellectual Disabilities. 2023.
35. Bigby, C., Beadle-Brown, J. Culture in Better Group Homes for People With Intellectual Disability at Severe Levels. Intellectual and developmental disabilities. 2016;54(5):316-31.
36. Department of Social Services, ARTD Consultants. National Disability Insurance Scheme Quality and Safeguarding Framework; Consultation report. 2015. Accessed on: 13 December 2024. Available from: https://engage.dss.gov.au/wp-content/uploads/2015/11/consultation_report_ndis_quality_safeguarding_framework.pdf.
37. The Looked After Children (Scotland) Regulations 2009, Scotland. 2009. Accessed on: 3 December 2024. Available from: https://www.legislation.gov.uk/ssi/2009/210/contents/made.
38. The Support and Assistance of Young People Leaving Care (Scotland) Regulations 2003, Scotland. 2003. Accessed on: 3 December 2024. Available from: https://www.legislation.gov.uk/ssi/2003/608/contents/made.
39. Health Information and Quality Authority. Standards Development Framework: a principles-based approach. 2021. Accessed on: 10 October 2024. Available from: https://www.hiqa.ie/sites/default/files/2021-09/Standards-Development-Framework-a-principles-based-approach.pdf.
40. Health Information and Quality Authority. National Standards for Residential Services for Children and Adults with Disabilities. 2013. Accessed on: 19 September 2024. Available from: https://www.hiqa.ie/reports-and-publications/standard/national-standards-residential-services-children-and-adults.
41. World Health Organization. Global report on health equity for persons with disabilities. 2022. Accessed on: 12 December 2024. Available from: https://www.who.int/publications/i/item/9789240063600.
42. World Health Organization. The WHO European Framework for action to achieve the highest attainable standard of health for persons with disabilities 2022–2030. 2022. Accessed on: 12 December 2024. Available from: https://iris.who.int/bitstream/handle/10665/364994/WHO-EURO-2022-6751-46517-67449-eng.pdf?sequence=1.
43. European Disability Forum. Independent living and de-institutionalisation Policy. Accessed on: 12 December 2024. Available from: https://www.edf-feph.org/independent-living-and-de-institutionalisation-policy/.
44. Fanagan, S., Caffrey, N., Cassidy, L., Beegan, J., Lynn, E. Overview of people engaging with disability services, 2024. 2024. Accessed on: 25 June 2025. Available from: https://www.hrb.ie/publication/overview-of-people-engaging-with-disability-services-bulletin-2024/.
45. Cramm, J.M., Nieboer, A.P. Validation of an instrument to assess the delivery of patient-centred care to people with intellectual disabilities as perceived by professionals. BMC health services research. 2017;17:1-11.
46. Rissanen, L., Ehrlich, C., Kendall, E., Muenchberger, H. Realizing person-centred care in residential care facilities for young adults with complex and chronic disabilities: the understanding, perception and beliefs of workers. European Journal for Person Centered Healthcare. 2014;2(2):190-200.

47. Ratti, V., Hassiotis, A., Crabtree, J., Deb, S., Gallagher, P., Unwin, G. The effectiveness of person-centred planning for people with intellectual disabilities: A systematic review. Res Dev Disabil. 2016;57:63-84.
48. World Health Organization. Delivering quality health services: a global imperative for universal health coverage: World Health Organization; 2018.
49. O'Dwyer, V., Behan, L., Weir, L., Connolly, D., Flynn, R. Translating national standards into practice: Supporting social care professionals. Journal of Social Care. 2020;3(1):1.
50. Health Information and Quality Authority. International review of the methodologies for developing national standards and guidance for health and social care services. 2018. Accessed on: 12 December 2024. Available from: https://www.hiqa.ie/sites/default/files/2018-11/International_Review_of_methodologies_for_developing_standards.pdf.
51. Health Act 2007, Ireland. 2007. Accessed on: 20 September 2024. Available from: https://www.irishstatutebook.ie/eli/2007/act/23/enacted/en/html.
52. Health Information and Quality Authority. Standards Development Framework: a principles-based approach. 2021. Accessed on: 19 December 2024. Available from: https://www.hiqa.ie/sites/default/files/2021-09/Standards-Development-Framework-a-principles-based-approach.pdf.
53. Health Information and Quality Authority. What is a designated centre? A guide to understanding the definition of designated centres. 2022. Accessed on: 29 September 2024. Available from: https://www.hiqa.ie/sites/default/files/2022-06/What-is-a-designated-centre_a-guide-to-understanding-the-definition.pdf.
54. S.I. No. 366/2013 - Health Act 2007 (Registration of Designated Centres for Persons (Children and Adults) with Disabilities) Regulations 2013, Ireland. 2013. Accessed on: 12 Sept 2024. Available from: https://www.irishstatutebook.ie/eli/2013/si/366/made/en/print.
55. S.I. No. 367/2013 - Health Act 2007 (Care and Support of Residents in Designated Centres for Persons (Children and Adults) with Disabilities) Regulations 2013, Ireland. 2013. Accessed on: 12 September 2024. Available from: https://www.irishstatutebook.ie/eli/2013/si/367/made/en/print.
56. Health Information and Quality Authority. Disability register. Accessed on: 25 June 2025. Available from: https://www.hiqa.ie/areas-we-work/disability-services.
57. Health Information and Quality Authority. Five years of regulation in designated centres for people with a disability. 2019. Accessed on: 24 December 2024. Available from: https://www.hiqa.ie/sites/default/files/2019-08/HIQA-DCD-5-Year-Regulation-Report-2019.pdf.
58. Department of Children Equality Disability Integration and Youth. Ireland and the UNCRPD. 2023. Accessed on: 29 October 2024. Available from: https://www.gov.ie/en/publication/c9352-ireland-and-the-uncrpd/.
59. Department of Children Equality Disability Integration and Youth. What the UNCRPD is. 2023. Accessed on: 18 October 2024. Available from: https://www.gov.ie/en/publication/b47d7-what-is-the-uncrpd/.
60. Department of Justice and Equality. National Disability Inclusion Strategy (2017-2021). 2020. Accessed on: 22 July 2025. Available from: https://assets.gov.ie/static/documents/national-disability-inclusion-strategy-2017-2021.pdf.

61. S.I. No. 461/2024 - Health (Miscellaneous Provisions) (No. 2) Act 2024 (Commencement) Order 2024, Ireland. 2024. Accessed on: 17 January 2024. Available from: https://www.irishstatutebook.ie/eli/2024/act/29/enacted/en/html.
62. Patient Safety (Notifiable Incidents and Open Disclosure) Act 2023, Ireland. 2023. Accessed on: 17 December 2024. Available from: https://www.irishstatutebook.ie/eli/2023/act/10/enacted/en/html.
63. Health Information and Quality Authority. Guidance on a Human Rights-based Approach in Health and Social Care Services. 2019. Accessed on: 27 December 2024. Available from: https://www.hiqa.ie/sites/default/files/2019-11/Human-Rights-Based-Approach-Guide.PDF.
64. Health Information and Quality Authority. Applying a Human Rights-based Approach in Health and Social Care: Putting national standards into practice. 2021. Accessed on: 27 December 2024. Available from: https://www.hiqa.ie/reports-and-publications/guide/guidance-human-rights-based-approach-health-and-social-care-services.
65. Health Service Executive. Time to Move on from Congregated Settings: A Strategy for Community Inclusion. 2011. Accessed on: 24 December 2024. Available from: https://www.hse.ie/eng/services/list/4/disability/congregatedsettings/time-to-move-on-from-congregated-settings-%E2%80%93-a-strategy-for-community-inclusion.pdf.
66. Health Information and Quality Authority. National Standards for Adult Safeguarding. 2019. Accessed on: 24 January 2025. Available from: https://www.hiqa.ie/sites/default/files/2019-12/National-Standards-for-Adult-Safeguarding.pdf.
67. Department of Children Equality Disability Integration and Youth. Action Plan for Disability Services 2024 – 2026. 2023. Accessed on: 24 Januray 2025. Available from: https://www.gov.ie/pdf/?file=https://assets.gov.ie/278953/b4a9ef8b-29a5-43b1-8f34-5e4513ffa357.pdf#page=null.
68. Houses of the Oireachtas. HIQA's Overview Report - Monitoring and Regulation of Designated Centres for People with Disabilities in 2021: Discussion. 2022. Accessed on: 24 January 2025. Available from: https://www.oireachtas.ie/en/debates/debate/joint_committee_on_disability_matters/2022-10-27/2/.
69. Houses of the Oireachtas. HIQA Report 2022: Discussion. 2023. Accessed on: 24 January 2025. Available from.
70. Joint Committee on Disability Matters. Aligning Disability Funding with the United Nations Convention on the Rights of Persons with Disabilities Budget 2025 Pre-Budget Submission. 2024. Accessed on: 24 January 2025. Available from: https://data.oireachtas.ie/ie/oireachtas/committee/dail/33/joint_committee_on_disability_matters/reports/2024/2024-06-26_aligning-disability-funding-with-the-united-nations-convention-on-the-rights-of-persons-with-disabilities-budget-2025-pre-budget-submission_en.pdf.
71. Health Information and Quality Authority, Mental Health Commission. Draft Overarching National Standards for the Care and Support of Children using Health and Social Care Services. 2021. Accessed on: 4 April 2025. Available from: https://www.hiqa.ie/reports-and-publications/consultation/draft-overarching-national-standards-care-and-support.

72. Health Information and Quality Authority. International review of the methodologies for developing national standards and guidance for health and social care service. 2018. Accessed on: 23 October 2024. Available from: https://www.hiqa.ie/sites/default/files/2018-11/International_Review_of_methodologies_for_developing_standards.pdf.
73. Enabling Good Lives. Enabling Good Lives Definition. 2024. Accessed on: 27 November 2024. Available from: https://www.enablinggoodlives.co.nz/about-egl/egl-definition/.
74. Scottish Government. Definitions of Learning Disability, Autism and Neurodiversity: FOI release. 2023. Accessed on: 12 December 2024. Available from: https://www.gov.scot/publications/definitions-of-learning-disability-autism-and-neurodiversity-foi-release/.
75. Care Inspectorate. Corporate Plan 2022-2025 Care. It's what we do. 2022. Accessed on: 19 November 2024. Available from: https://www.careinspectorate.com/images/documents/6663/Care%20Inspectorate%20Corporate%20Plan%202022.pdf.
76. Regulation of Care (Scotland) Act 2001, Scotland. 2001. Accessed on: 5 November 2024. Available from: https://www.legislation.gov.uk/asp/2001/8/contents.
77. Health Standards Organization. What is HSO? 2025. Accessed on: 22 July 2025. Available from: https://healthstandards.org/about/.
78. Care Standards Act 2000, UK. 2000. Accessed on: 26 September. Available from: https://www.legislation.gov.uk/ukpga/2000/14/contents.
79. Care Quality Commission. About us. 2025. Accessed on: 22 July 2025. Available from: https://www.cqc.org.uk/about-us.
80. Standards New Zealand. About Standards New Zealand. 2015. Accessed on: 22 July 2025. Available from: https://www.standards.govt.nz/about/who-we-are.
81. JASANZ. About us. 2025. Accessed on: 24 July 2025. Available from: https://www.jasanz.org/about-us.
82. Regulation and Quality Improvement Authority. RQIA Provider Guidance updated June 2023; Adult Residential Care Homes. 2023. Accessed on: 23 October 2024. Available from: https://www.rqia.org.uk/RQIA/files/3c/3c9f8451-6991-49f1-af97-70fcf55a01bb.pdf.
83. Department of Health. Regulation and Quality Improvement Authority. Accessed on: 22 July 2025. Available from: https://www.health-ni.gov.uk/topics/regulation-and-quality-improvement-authority#:~:text=The%20RQIA%20is%20an%20independent%20body%20responsible%20for,encouraging%20improvements%20in%20the%20quality%20of%20those%20services.
84. Northern Ireland Orders in Council. The Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003. 2003. Accessed on: 3 December 2024. Available from: https://www.legislation.gov.uk/nisi/2003/431/contents.
85. Scottish Government. Getting it right for every child. 2006. Accessed on: 22 November 2024. Available from: https://www.gov.scot/policies/girfec/.
86. Care Inspectorate. A quality framework for children and young people in need of care and protection. 2022. Accessed on: 4 December 2024. Available from:

https://www.careinspectorate.com/images/documents/5865/Quality%20framework%20for%20children%20and%20young%20people%20in%20need%20of%20care%20and%20protection%20NOV%202022.pdf.
87. Children and Young People (Scotland) Act 2014, Scotland. 2014. Accessed on: 18 November 2014. Available from: https://www.legislation.gov.uk/asp/2014/8/data.pdf.
88. Care Inspectorate Wales. Regulations, statutory guidance and National Minimum Standards: Adult and children's services. Accessed on: 25 October 2025. Available from: https://www.careinspectorate.wales/regulations-statutory-guidance-and-national-minimum-standards-adult-and-childrens-services.
89. Acts of the National Assembly for Wales. Regulation and Inspection of Social Care (Wales) Act 2016. 2016. Accessed on: 5 November 2024. Available from: https://www.legislation.gov.uk/anaw/2016/2/contents.
90. National Disability Insurance Scheme Quality and Safeguards Commission. NDIS Practice Standards and Quality Indicators. 2021. Accessed on: 2 December 2024. Available from: https://www.ndiscommission.gov.au/sites/default/files/2022-02/ndis-practice-standards-and-quality-indicatorsfinal1.pdf.
91. National Disability Insurance Scheme Quality and Safeguards Commission. NDIS Quality and Safeguards Commission; What we do. 2024. Accessed on: 2 December 2024. Available from: https://www.ndiscommission.gov.au/about-us/what-we-do.
92. National Disability Insurance Scheme Quality and Safeguards Commission. NDIS Code of Conduct. 2024. Accessed on: 2 December 2024. Available from: https://www.ndiscommission.gov.au/about/ndis-code-conduct.
93. Australian Government; Department of Social Services. National Standards for Disability Services. 2023. Accessed on: 20 January 2025. Available from: https://pwd.org.au/about-us/about-disability/national-standards-for-disability-services-nsds-2014/.
94. Australian Government; Department of Social Services. National Standards for Disability Services. 2013. Accessed on: 2 December 2024. Available from: https://www.dss.gov.au/disability-advocacy/resource/national-standards-disability-services.
95. National Insitute for Health and Care Excellence. What we do. 2025. Accessed on: 23 July 2025. Available from: https://www.nice.org.uk/about/what-we-do.
96. Regeringen, Mininistry of Social Affairs. Commission on a comprehensive monitoring system for disability policy [Uppdrag om ett samlat uppföljningssystem för funktionshinderspolitiken]. 2011. Accessed on: 10 December 2024. Available from: https://www.regeringen.se/contentassets/32d91d6808d04dc5be9922b9b9316b92/uppdrag-om-ett-samlat-uppfoljningssystem-for-funktionshinderspolitiken/.
97. Swedish Agency for Participation. Disability Policy in Sweden; An overview. 2023. Accessed on: 12 December 2024. Available from: https://www.mfd.se/contentassets/ce5c28c151bd440f954cef9f8037f2a6/2023-20-disability-policy-in-sweden-an-overview.pdf.
98. Health Improvement Scotland. Independent Healthcare Regulation; Inspection Methodology. 2023. Accessed on: 19 November 2024. Available from:

https://www.healthcareimprovementscotland.scot/wp-content/uploads/2024/02/IHC-Inspection-Methodology-July-2023.pdf.
99. Scottish Parliament. Children and Young People (Scotland) Act 2014. 2014. Accessed on: 18 November 2014. Available from: https://www.legislation.gov.uk/asp/2014/8/data.pdf.
100. Walsh, C., Duggan, C., Waldron, C., Vaughan, E., Geaney, F., Carrigan, M., et al. The characteristics of person-centred care in residential services for children and adults with disabilities: A scoping review protocol. 2025. Accessed on: 06 May 2025. Available from: https://osf.io/rx7yb.
101. Walsh, C., Duggan, C., Waldron, C., Vaughan, E., Geaney, F., Carrigan, M., et al. The characteristics of person-centred care in residential services for children and adults with disabilities: a scoping review protocol [version 1; peer review: awaiting peer review]. HRB Open Research. 2025;8(57).
102. Peters, M.D.J., Godfrey, C.M., Khalil, H., McInerney, P., Parker, D., Soares, C.B. Guidance for conducting systematic scoping reviews. JBI Evidence Implementation. 2015;13(3):141-6.
103. Moher, D., Shamseer, L., Clarke, M., Ghersi, D., Liberati, A., Petticrew, M., et al. Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015 statement. Systematic reviews. 2015;4:1-9.
104. Aromataris, E., Lockwood, C., Porritt, K., Pilla, B., Jordan, Z. JBI Manual for Evidence Synthesis. 2024. Accessed on: 11 November 2024. Available from: https://jbi-global-wiki.refined.site/space/MANUAL.
105. Haddaway, N.R., Grainger, M.J., Gray, C.T. Citationchaser: A tool for transparent and efficient forward and backward citation chasing in systematic searching. Research Synthesis Methods. 2022;13(4):533-45.
106. Howard, E.P., Martin, L., Heckman, G.A., Morris, J.N. Does the Person-Centered Care Model Support the Needs of Long-Term Care Residents With Serious Mental Illness and Intellectual and Developmental Disabilities? Frontiers in psychiatry. 2021;12:704764.
107. Humphreys, L., Bigby, C., Araten-Bergman, T., Iacono, T. Active Support Measure: A multilevel exploratory factor analysis. Journal of Intellectual Disability Research. 2024;68(6):564-72.
108. Jones, E. Back to the future: developing competent residential services for people with intellectual disabilities and challenging behaviour. Advances in Mental Health & Intellectual Disabilities. 2013;7(1):5-17.
109. Kåhlin, I., Kjellberg, A., Hagberg, J.E. Choice and control for people ageing with intellectual disability in group homes. Scandinavian journal of occupational therapy. 2016;23(2):127-37.
110. McCausland, D., Murphy, E., McCarron, M., McCallion, P. The potential for person-centred planning to support the community participation of adults with an intellectual disability. Journal of Intellectual Disabilities. 2022;26(3):603-23.
111. Prager, B.C., Broder, S.M., Natowicz, M.R. A picture is worth a thousand words: A proposal to incorporate video into the evaluation of adults with intellectual or developmental disability living outside the home. Front Public Health. 2022;10:887714.

112. Richards, M. Whorlton Hall, Winterbourne … person-centred care is long dead for people with learning disabilities and autism. Disability & Society. 2020;35(3):500-5.
113. Salmon, R., Holmes, N., Dodd, K. Reflections on change: supporting people with learning disabilities in residential services. British Journal of Learning Disabilities. 2014;42(2):141-52.
114. Smith, D., Carey, E. Person-centred care planning for clients with complex needs. Learning Disability Practice. 2013;16(10):20-3.
115. Thalen, M., van Oorsouw, W.M.W.J., Volkers, K.M., Taminiau, E.F., Embregts, P.J.C.M. Integrated Emotion-Oriented Care for Older People With ID: Defining and Understanding Intervention Components of a Person-Centered Approach. Journal of Policy and Practice in Intellectual Disabilities. 2021;18(3):178-86.
116. Verdugo, M., Schalock, R.L., Gómez, L.E., Navas, P. A Systematic Approach to Implementing, Evaluating, and Sustaining the Shared Citizenship Paradigm in the Disability Field. Behav Sci (Basel). 2023;13(12).
117. Kelly C., McConkey R., S, C. A case-study of policy change in residential service provision for adult persons with intellectual disability in Ireland. Health & social care in the community. 2019;27(5):e760-e8.

Appendices

Appendix 1. Eligibility criteria for the scoping review

Inclusion Criteria	Exclusion Criteria
▪ Children and adults of all ages with a permanent or likely permanent intellectual, sensory and physical disabilities. ▪ Evidence from the perspectives of the service users, their families and residential service staff members.	▪ People with age-related disabilities only. ▪ Children and adults with mental health illnesses only. ▪ Patients receiving palliative care or people at end of life. ▪ Evidence focused on outcomes for staff only.
▪ Evidence related to person-centred care and or patient-centred care.	▪ Articles reporting on interventions, treatments, or the use of technological aids, unless they consider person-centred care.
▪ All residential services and residential respite services. ▪ For the purposes of this review, the HIQA definition of residential services will be used: A 'residential service' is one that is comprised of both accommodation and care and or support services provided to children and adults with disabilities living in residential settings, on a short or long-term basis, whether or not it is their sole place of residence.	▪ Evidence related to home care, domiciliary care, non-residential services care. ▪ Articles focused on primary care, community care, hospital or acute care settings. ▪ Rehabilitation centres.
▪ Peer-reviewed literature, all study designs.	▪ Non-peer-reviewed, protocols.
▪ Evidence published in or after 2013 ▪ No filters will be applied to the search strategy.	▪ Evidence published before 2013.

Appendix 2. Search strategy for Medline Complete

SEARCH STRATEGIES

Database Name	Medline via Ebscohost
Date search was run	18 February 2025

#	Query	Limiters/Expanders	Results
S1	(MH "Persons with Disabilities+")	Expanders - Apply equivalent subjects	76,962
S2	(MH "Intellectual Disability+")	Expanders - Apply equivalent subjects	109,337
S3	(MH "Communication Disorders+")	Expanders - Apply equivalent subjects	71,353
S4	TI Disable* OR AB Disable*	Expanders - Apply equivalent subjects	30,533
S5	TI disabilit* OR AB disabilit*	Expanders - Apply equivalent subjects	269,578
S6	AB ((intellect* OR cognitive OR learning OR physical* OR mental*) N3 (deficien* or difficult* or disab* or disorder* or handicap* or impair* or incapacit*)) OR TI ((intellect* OR cognitive OR learning OR physical* OR mental*) N3 (deficien* or difficult* or disab* or disorder* or handicap* or impair* or incapacit*))	Expanders - Apply equivalent subjects	311,915
S7	S1 OR S2 OR S3 OR S4 OR S5 OR S6	Expanders - Apply equivalent subjects	703,211
S8	(MH "Residential Facilities+")	Expanders - Apply equivalent subjects	60,423
S9	(MH "Nursing Homes+") OR (MH "Respite Care")	Expanders - Apply equivalent subjects	47,259
S10	AB ((residential OR nursing) N1 (home* or facilit* or setting* OR centre* OR center* OR service* OR institution*)) OR TI ((residential OR nursing) N1 (home* or facilit* or setting* OR centre* OR center* OR service* OR institution*))	Expanders - Apply equivalent subjects	60,569
S11	(TI "care home*" OR "respite care" OR "supported accommodation") OR (AB "care	Expanders - Apply equivalent subjects	8,002

#	Query	Limiters/Expanders	Results
	home*" OR "respite care" OR "supported accommodation")		
S12	AB (("continuing care" or disabled or "long term care") N2 (lodge* or facilit* or home* or residence* or centre* or center*)) OR TI (("continuing care" or disabled or "long term care") N2 (lodge* or facilit* or home* or residence* or centre* or center)	Expanders - Apply equivalent subjects	10,379
S13	S8 OR S9 OR S10 OR S11 OR S12	Expanders - Apply equivalent subjects	102,105
S14	(MH "Patient-Centered Care+")	Expanders - Apply equivalent subjects	25,892
S15	AB ((patient* or person or people or individual or "service user" or client) N3 (tailor* or centered or centred or centric* or focus* or oriented)) OR TI ((patient* or person or individual or "service user" or client) N3 (tailor* or centered or centred or centric* or focus* or oriented))	Expanders - Apply equivalent subjects	141,863
S16	S14 OR S15	Expanders - Apply equivalent subjects	154,250
S17	S7 AND S13 AND S16	Expanders - Apply equivalent subjects	362
S18	S7 AND S13 AND S16	Limiters - Publication Date: 20130101-	248

Appendix 3. Characteristics of the included articles in the scoping review

No.	Article	Country	Study Design	From the perspective of	Age	Context
1	Bigby & Beadle-Brown 2016(35)	Australia	Qualitative	Staff in residential service	Between 18 and 65	Small settings*
2	Blessing et al. 2025(24)	USA	Qualitative	Multiple perspectives	Between 18 and 65	Unclear
3	Cramm & Nieboer P 2019(32)	The Netherlands	Quantitative	Family member	Not relevant	Institutional settings **
4	Cramm & Nieboer 2017(33)	The Netherlands	Quantitative	Staff in residential service	Not relevant	Mixed settings
5	Gadd 2020(25)	Ireland	Qualitative	Person with a disability	Over 18	Respite service
6	Gjermestad 2017(26)	Norway	Qualitative	Staff in residential service	Between 18 and 65	Unclear
7	Howard et al. 2021(106)	USA	Quantitative	Other	Over 18	Unclear
8	Humphreys et al. 2024(107)	Australia	Quantitative	Other	Over 18	Unclear
9	Jackman-Galvin & Partridge 2022(30)	Ireland	Qualitative	Multiple perspectives	Not reported	Unclear
10	Jones 2013(108)	Wales	Other	Other	Not reported	Unclear
11	Kåhlin et al. 2016(109)	Sweden	Qualitative	Multiple perspectives	Over 18	Small settings
12	McCausland et al. 2022(110)	Ireland	Mixed-methods	Multiple perspectives	Over 18	Small settings
13	Ouellette-Kuntz et al. 2019(27)	Canada	Mixed-methods	Other	Between 18 and 65	Small settings
14	Özdemir et al. 2023(28)	England	Mixed-methods	Staff in residential service	Not reported	Small settings
15	Prager et al. 2022(111)	USA	Other	Other	Not reported	Unclear
16	Richards 2020(112)	England	Other	Other	Not reported	Institutional settings
17	Salmon et al. 2014(113)	England	Qualitative	Staff in residential service	Not reported	Small settings
18	Schaap et al. 2021(29)	The Netherlands	Mixed-methods	Staff in residential service	Over 18	Small settings
19	Smith & Carey 2013(114)	Ireland	Other	Staff in residential service	Over 65	Small settings

No.	Article	Country	Study Design	From the perspective of	Age	Context
20	Thalen et al. 2023(31)	The Netherlands	Qualitative	Staff in residential service	Not reported	Unclear
21	Thalen et al. 2021(115)	The Netherlands	Qualitative	Staff in residential service	Not reported	Unclear
22	Verdugo et al. 2023(116)	Spain	Other	Other	Not reported	Unclear
23	Wallin et al. 2023(34)	Sweden	Qualitative	Other	Under 18	Small settings
*Small settings <10 people in any one house ** Institutional settings -10 or more people are accommodated						

Appendix 4: Definitions of person-centred care

No.	Definitions of person-centred care
1	Working practices were person centred as hypothesised and characterised by attentiveness, relationships, flexibility, and momentary fun interactions.(35)
2	To be person-centred is "to put the person in the middle of our thinking and get to know the person in fresh and vital ways that set the pattern for everything else we do in partnership with that person".(24)
3	As a values-based philosophy and intentional practice, person-centred planning can shift the social position (and perception) of people with disabilities by emphasising what they can contribute to society.(24)
4	A commonly used definition of person-centred care is: 'healthcare that establishes a partnership among practitioners, patients, and their families (when appropriate) to ensure that decisions respect patients' wants, needs, and preferences and that patients have the education and support they need to make decisions and participate in their own care' (32)
5	Person-centred care is defined as "healthcare that establishes a partnership among practitioners, patients, and their families (when appropriate) to ensure that decisions respect patients' wants, needs, and preferences and that patients have the education and support they need to make decisions and participate in their own care".(33)
6	Person-centredness; a set of beliefs, attitudes and expectations about the right and capacity of a person with a disability to live their life in accordance with their aspirations, needs and abilities.(25)
7	A truly person-centred service should be built on the values of respect, empowerment, choice, inclusion, and partnership.(25)
8	Person-centred care in this context demands sensitive, passionate and effective staff who listen to and try to understand and interpret the meaning of individuals' non-verbal expressions.(26)
9	Person-centred care of persons with profound intellectual and multiple disabilities involves providing and organising services rooted in the needs of the people receiving care – meaning emphasising and acknowledging each individual's unique abilities and needs and getting close to their perspective.(26)
10	Person-centredness; an approach to practice established through the formation and fostering of healthful relationships between all providers, service users and others significant to them in their lives. It is underpinned by values of respect and understanding. It is enabled by cultures of empowerment that foster continuous approaches to practice development.(30)
11	A person-centred approach is one that focuses on the person's strengths, goals and abilities; promotes and facilitates opportunities to make meaningful choices; and involves collaboration with natural supports (for example, family, friends).(27)
12	Adopting a person-centred approach is to focus on the needs of the individual, recognising people's differences and taking the time to understand their preferences and values.(28)
13	Person-centred approaches are meant to develop a self-determination to help people take control of their lives.(112)
14	In caring for older people with intellectual disabilities, person-centred methods are promising and may contribute to the shift from task-focused to more supportive care.(29)

15	Person-centred dementia care can be specified as: valuing people with dementia (V); using an individual approach that recognises the uniqueness of the person (I); making an effort to understand the world from the perspective of the person (P); and providing a supportive social environment (S).(29)
16	Person-centred care provided by professional staff should comply with four major elements summarised in Brooker's VIPS framework: (a) an assertion of the absolute value of all human lives, regardless of age or cognitive ability; (b) an individualised approach, recognising the uniqueness of the person; (c) an understanding of the world from the perspective of the person; (d) a positive social psychology, enabling the person to experience relative wellbeing.(29)
17	Person-centred care puts the person at the centre of care services, rather than the disease.(29)
18	Person-centred care; care approaches and practices that see the person as a whole, with many levels of needs and goals, with these needs coming from their own personal social determinants of health.(31)
19	Person-centred care can be seen as a philosophical framework that guides delivery of healthcare and is based on individuals' values and preferences.(31)
20	Person-centredness; the understanding of needs should be combined with approaches of user involvement, to ensure that support and care are consistent with individual preferences and goals.(34)

Appendix 5: List of concepts and characteristics mapped to the four principles of person-centred care

Principle	Concept	Characteristic
Principle 1: A human rights-based approach	**Autonomy**	Child involvement
		Children's involvement in decision-making
		Choice and control
		Clients are in charge of their own care (x2)*
		Compatible groupings
		Empowerment
		Helping people to have a voice
		Inclusion
		Issues of choice
		Opportunities for independence
		Personal choice
		Recognising group home residents as human beings with ideas and opinions
		Support staff focus on the client's perspective to better understand the wishes, needs and behaviour of the client
		Taking patients' preferences into account (x2)
	Promoting and protecting human rights	An assertion of the absolute value of all human lives, regardless of age or cognitive ability
		Healthcare professionals treat clients with dignity and respect (x2)
		Helpful de-escalation techniques
		Providing dignity, love and care
		Respecting the individual being cared for
		The values and ambitions of people with learning disabilities and autism need to be the power
		To respect the person in the collective
		Valuing people
		Clients have privacy (x2)
	The living environment	Healthcare professionals take clients' preferences for support with their daily living needs into account (x2)
		Physical comfort (x2)
		Time and space for myself
		User involvement in respite service design and provision
	Support to understand relevant information	Clients can access their care records (x2)
		Healthcare professionals support clients to be in charge of their care (x2)
		Information and education (x2)
	Involving family and friends in line	Family and friends (x2)
		Family involvement

Principle	Concept	Characteristic
	with the persons wishes	Healthcare professionals involve relatives in decisions regarding patients' care (x2)
		Healthcare professionals pay attention to loved ones in their role as carers for clients (x2)
		Healthcare professionals pay attention to the needs of clients' family and friends (x2)
		Support staff create room for participation and perceptions from the client's informal network
Principle 2: Safety and wellbeing	**Social and family networks**	A chance to spend time with friends and make new friends
		Build and maintain relationships
		Community participation
		Creating room for the informal networks of service users
		Healthcare professionals involve relatives in the emotional support of clients (x2)
		Providing a supportive social environment
		Support staff create room for participation and perceptions from the client's informal network
	Person-centred approaches to planning	A person-centred approach to planning
		Person-centred planning (x4)
		Person-centred planning and evaluation
		Person-centred care plans
		Support staff try to adequately adjust to the client's current needs when practising IEOC
		Tailor lifestyle categories to the person's expressed desires
	Involvement of the person in their own care	Engage the person and their team in identifying action to take to move forward in the plan
		Healthcare professionals support clients to be in charge of their care (x2)
		Healthcare professionals take clients' preferences for support with their daily living needs into account (x2)
		Inclusion
		Increased staffing efforts to involve children in support development
		Opportunities for independence
	Improving wellbeing and quality of life	A positive social psychology, enabling the person to experience relative wellbeing
		Service orientation
		Fostering a positive environment
		Fun
		Healthcare is focused on improving the quality of life of clients (x2)
		Healthful relationships
		Access to care (x2)

Principle	Concept	Characteristic
	The physical environment	Clear directions are provided to and inside the building (x2)
		The building is accessible to all clients (x2)
		The role of the environment
	Creating a homely and safe environment	Community-based service structure
		Compatible groupings
		Same-gender groupings
Principle 3: Responsiveness	**Positive relationships with staff**	Attentive
		Connecting with service users
		Emotional support (x2)
		Familiar staff
		Healthcare professionals are well informed; clients need to tell their story only once (x2)
		Increased knowledge about and positive relationships with the individuals for whom they care
		Momentary fun interactions
		Positive relationships with staff
		Relational
		Support staff connect with the client in order to build a relationship with them
		Asking questions
	Communication	Discussion of the individual's interests and likes and dislikes
		Ensuring a person-centred approach by listening to the voices of this client group and their carers
		Learning the residents' preferred communication methods
		Listen to person's hopes and dreams for each identified category
		Support staff focus on the client's perspective to better understand the wishes, needs and behaviour of the client
		Taking patients' preferences into account (x2)
		The values and ambitions of people with learning disabilities and autism need to be the power
	An individualised approach to care and support	Understanding their perspective
		An individualised approach, recognising uniqueness of the person
		Celebrate the person's unique gifts and attributes
		Focusing on the perspective of service users
		Making an effort to understand the world from the perspective of the person
		Personhood
		Reflect on the person's accomplishments within the chosen categories
		To respect the person in the collective

Principle	Concept	Characteristic
		Treating that person as a unique individual
		Using an individual approach that recognises the uniqueness of the person
	Coordination of care and transitions	Care is well coordinated among professionals (x2)
		Clients get skilled advice about care and support at home after discharge (x2)
		Clients who are transferred are well informed about where they are going, what care they will receive, and who will be their contact person (x2)
		Continuity and transition (x2)
		Coordination of care (x2)
		Healthcare professionals work as a team in care delivery to clients (x2)
		Support staff work in a team culture that is based on safety and trust
		When a client is transferred to another ward, relevant patient information is transferred as well (x2)
		Working in a safe and trusting team culture
	Person-centred approaches to care	A shift from a task-oriented way of working to a person-centred
		Active support
		Healthcare professionals pay attention to clients' anxiety about their situations (x2)
		Healthcare professionals pay attention to clients' anxiety over the impact of their illness on their loved ones (if applicable) (x2)
		Narrative competence
		Supporting residents took priority
		Training programme
	Adjusting care and support to peoples' needs	Support staff try to adequately adjust to the client's current needs when practising IEOC
		Adjusting to the current needs of service users
		Flexible
		Healthcare professionals pay attention to pain management (x2)
		Matters that may upset the service user or cause discomfort
		Physical comfort (x2)
Principle 4: Governance and accountability	**Access and availability of care and support**	Access to care (x2)
		Available and flexible supports
		It is easy to schedule an appointment (x2)
		Care is well coordinated among professionals (x2)
		Coordination of care (x2)

Principle	Concept	Characteristic
	Coordination of care and use of information	When a client is transferred to another ward, relevant patient information is transferred as well (x2)
	Ensuring appropriate grouping of residents	Same-gender groupings
		Helpful de-escalation techniques
		Persons with behaviour support needs
	Person-centred principles at an organisational level	Procedures
		The need to promote systems change
	Safe and trusting team culture	Support staff work in a team culture that is based on safety and trust
		Working in a safe and trusting team culture
*Characteristic appeared in more than one article, number appears in brackets		

Published by the Health Information and Quality Authority (HIQA).

For further information please contact:
Health Information and Quality Authority
George’s Court
George’s Lane
Smithfield
Dublin 7
D07 E98Y

+353 (0)1 814 7400
info@hiqa.ie
www.hiqa.ie