



**Health
Information
and Quality
Authority**

An tÚdarás Um Fhaisnéis
agus Cáilíocht Sláinte

Health Information
and Standards

Executive summary: Evidence review to inform the development of a set of principles to underpin future national standards for health and social care services

February 2021

Safer Better Care

About the Health Information and Quality Authority

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

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

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

Executive summary

The Health Information and Quality Authority (HIQA) is the statutory body established under the Health Act 2007 to drive high-quality and safe care for people using health and social care services in Ireland. One of HIQA's functions is to set standards, based on evidence, to drive improvement in health and social care services. HIQA also uses these standards as a tool to regulate and monitor health and social care services.

In 2018, HIQA's review of methodologies used internationally for developing national standards and guidance for health and social care services identified a move to developing overarching standards in the jurisdictions reviewed.⁽¹⁾ In addition, there is also a recognition that higher level and less prescriptive standards can be underpinned by principles. In line with emerging international evidence, HIQA has developed a draft set of principles to underpin all future national standards for health and social care services. These principles, once finalised, will be used as HIQA's standards development framework, instead of the eight-theme framework which HIQA has used to develop standards since 2012.⁽²⁾ These draft principles work together to achieve person-centred care and support.

The principles are being developed to be used consistently across all national standards developed by HIQA, irrespective of the setting or service type. The draft principles have been used in the development of the draft National Standards for Children's Social Services. A public consultation on these draft standards will commence in early 2021. This will be the first time the draft principles will be used and as such will be an opportunity to test them in practice and seek further feedback on their use. Following this testing of the principles, and once feedback has been reviewed and incorporated as appropriate, the principles will be finalised and used for all future national standards for health and social care services including any guidance and tools developed to support their implementation. This will not affect existing national standards, which will remain in place until such time as a decision is made, in line with HIQA's prioritisation process, to review and update them. Any such decision to review or update existing standards will be informed by consultation with stakeholders.

This document provides an overview of the evidence gathered to inform the move to a principle-based approach and the development of the draft set of principles. The principles, once finalised, will be published on the HIQA website.

Overview of findings

To inform the development of these principles, HIQA has undertaken a review of the current use of principles in health and social care services in Ireland, an international review and an academic literature review in line with its evidence synthesis

process.⁽³⁾ This review took account of published research, guidelines, frameworks, strategy documents, and legislation containing or underpinned by values or principles.

Many jurisdictions recognise that one set of high level principles can underpin all health and social care standards, irrespective of the service or setting. The review also identified a consistency of principles in the jurisdictions and literature reviewed. A summary of the key findings on adopting a principles-based approach and the development of the draft principles is set out below.

Key findings on adopting a principles-based approach

Principles and values are used in a large number of key documents identified in the international review. However, there is no clear definition of principles and the use of the term in standards, guidance or associated documents is inconsistent. Despite inconsistencies in how principles are used, common principles to underpin health and social care, irrespective of service or setting, were identified.

There were a number of key findings on how principles are used in health and social care legislation, strategy, standards, guidance and codes of practice in the seven jurisdictions examined.* These are set out below.

Use of principles in legislation

Principles have been used in legislation in a number of jurisdictions to highlight the importance of particular concepts in health and social care, and there is a move to setting out guiding principles in legislation and associated codes of practice. The principles set out in legislation have influenced national health and social care frameworks, policies, standards and guidance.

This is most evident in social care legislation in the UK, with the Social Services and Well-being (Wales) Act 2014,⁽⁴⁾ the Public Bodies (Joint Working) (Scotland) Act 2014,⁽⁵⁾ and the Care Act 2014 (England),⁽⁶⁾ which all include principles relating to wellbeing. In addition, these acts all provided a radical shift from existing duties on local authorities to provide particular services, to the concept of 'meeting needs' of the individual and thus delivering more responsive services. These principles have helped inform the development of health and social care regulations and standards in these jurisdictions and the approach to inspection and regulation of these services. A recent review of health and disability services in New Zealand, published in 2020, also recommends the move to common principles and or values across

* The seven jurisdictions examined as part of the international review were Northern Ireland, England, Scotland, Wales, Australia, New Zealand and Canada.

health and social care services and for these values to be mandated in a legislated charter.⁽⁷⁾

In an international context, principles and values are used within legislation to ensure that a number of core human rights principles are provided with a statutory footing globally. Ratification of international human rights treaties within jurisdictions examined reflects a strong commitment to the protection and promotion of human rights.

There is a clear move in a number of jurisdictions towards setting out guiding principles for health and social care services in legislation. Given that principles can be understood as fundamental values or goals that are needed to underpin good services, plans, practices and processes and apply regardless of the service setting or type, there is an opportunity in developing high level guiding principles that can be generalised to all legislation, and statutory instruments focused on people's care and support, regardless of the services that they are using. This would ensure that national policy, standards and guidance all followed the same guiding principles to provide a common understanding across health and social care services and help ensure integrated and consistent care and support for people.

Use of principles in national standards and strategy documents

HIQA's 2018 international review also identified a move to overarching standards and that trend has continued in the last number of years.⁽¹⁾ For example, in New Zealand the recent draft amended standards for health and disability services care have amalgamated and replaced a number of individual standards.⁽⁸⁾

In addition, there is also a recognition that higher level and less prescriptive standards can be underpinned by principles. This is most clearly seen in *Scottish Health and Social Care Standards* which are underpinned by five principles: dignity, compassion, be included, responsive care and support, and wellbeing.⁽⁹⁾ This is also evident in existing overarching quality standards from Northern Ireland which include a set of common principles and values.⁽¹⁰⁾ Recent reviews of the Welsh health and social care system and associated strategy documents have also identified the need for a common set of principles or values to promote integration across health and social services.^(11,12,13)

There is also clear evidence from a number of jurisdictions of how the use of principles in key pieces of health and social care legislation has had a role in shaping national standards, regulations, codes of practice, guidance and strategy documents. The principles set out in the overarching legislation have been adapted and incorporated into the documents as guiding or underpinning principles.

Use of principles in codes of practice

Codes of practice are developed by professional regulatory bodies for individual health and social care professionals to apply in their day-to-day practice as opposed to standards developed to apply to health and social care services. However, across jurisdictions they share common themes with the principles outlined in standards and guidance documents for health and social care services. The principles that apply to individual health and social professionals reflect and complement the principles that apply to the overall service they work in.

Development of the draft principles

This document outlines the evidence that informed the development of the draft principles. In line with HIQA's Health Information and Standards Directorate's evidence synthesis process,⁽³⁾ this review took account of published research, guidelines, frameworks, strategy documents, and legislation containing or underpinned by values or principles. This included:

- **A review of the use of overarching principles in Ireland**, including an overview of standards, guidance, frameworks, strategies, legislation and policy.
- **An international review of the use of overarching principles** in Scotland, England, Wales, Northern Ireland, Australia, Canada and New Zealand.
- **A literature review** of relevant academic material which examined the evidence-based principles that underpin safe, high-quality, person-centred care in health and social care settings

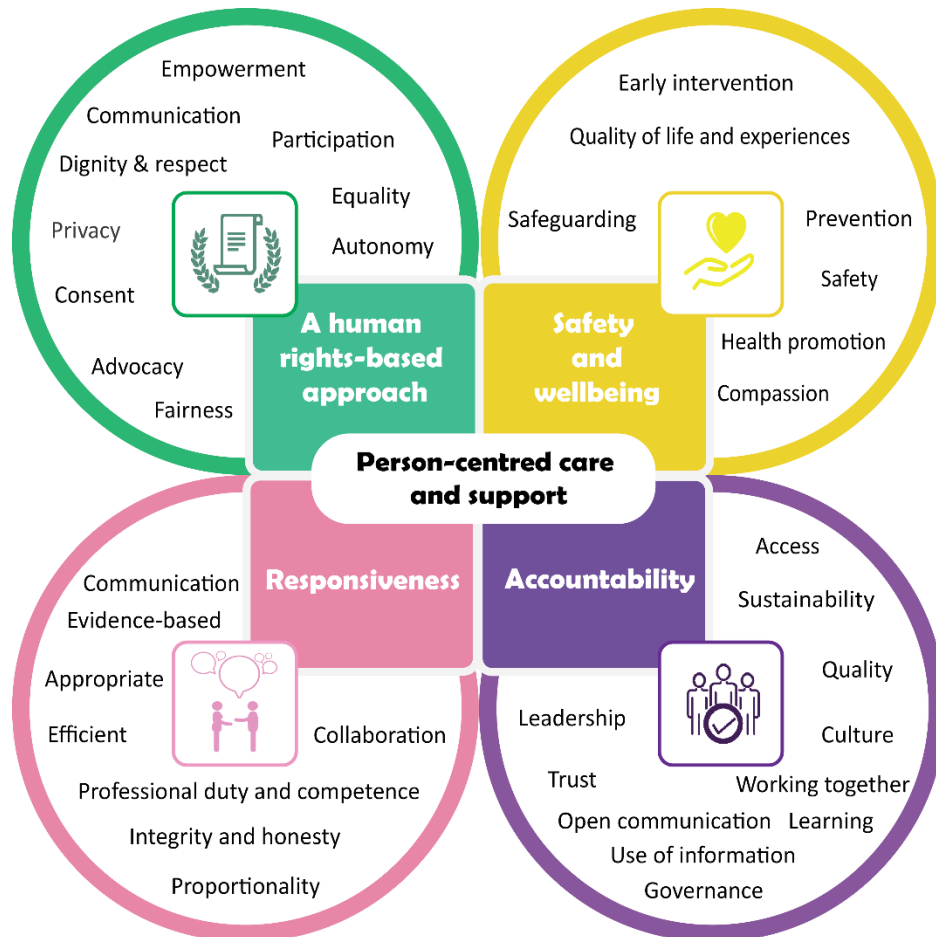
The information gathered as part of the evidence synthesis and international review was collated and analysed by the HIQA Project Team and used as the evidence base to develop the draft principles. Based on the findings, four draft principles emerged, underpinned by the core concept of person-centredness. These principles are:

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

It is recognised that these principles are interlinked and can overlap in places. 'Person-centred care and support' is not viewed as a principle in itself, rather it is an approach to care, with the four principles working together to achieve person-centred care and support.

Figure 1 below sets out the four principles and includes examples of the components of each principle, as identified through this evidence review. It 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.

Figure 1 Draft principles to underpin national standards for health and social care services



The following section provides a summary of the evidence from the international review and the evidence synthesis that informed the development of these four principles:

A human rights-based approach

In recent years, there has been an increased international focus on human rights, empowerment, choice and autonomous decision-making within health and social care sectors. This is strongly reflected in the principles included in standards, guidance, and strategy documents in the jurisdictions included in this review. This focus stems from the introduction of international human rights legislation, which places an obligation on health and social care providers to uphold the human rights of people using their services.

The FREDA principles of Fairness, Respect, Equality, Dignity and Autonomy are used by a number of organisations in their human rights-based approach to regulation and monitoring of health and social care services, including the Care Commission in England and the Care Inspectorate Wales. In addition, a number of jurisdictions have included individual principles relating to human rights in their national standards. For example, this can be seen in Scotland where 'dignity and respect' and 'be included' are two of the five principles used to underpin their standards.⁽⁹⁾

A human rights-based approach emerged from the literature across multiple health and social care settings as respecting, protecting and promoting the human rights of the person receiving care and support at all times. These rights, in a health and social care context, mean rights to participate in their care and support, fairness in terms of access and delivery of care and support, being treated with dignity and respect and not discriminated against for any reason, having the freedom to choose and give consent where this is possible, and being empowered to self-manage and be independent.

Of note, while a human rights-based approach to care and support does not necessarily guarantee good health for the person, or the availability of services, it aims to achieve the highest standard of care and support possible, and highlight where this standard is not achieved.

Safety and wellbeing

Safety and wellbeing emerged from the literature across a range of health and social care settings, both in terms of the physical safety and wellbeing of the person receiving care and support, and also in terms of a person's sense of psychological safety. Safety, in various health and social care settings, was consistently found to be facilitated by the daily work of health and social care professionals and access to adequate resources, but this needs to be supported by the culture and environment of the health and social care organisation.

The principle 'wellbeing' has been described in legislation, national standards, guidance and strategy documents as a broad concept which includes, for example, physical and mental health and emotional wellbeing, protection from abuse and neglect, autonomy and control over day-to-day life, participation in work, education, training or recreation and contribution to society.^(4,5,6,8,9,14) Thus, wellbeing is tied to the concept of a holistic approach to care and support that does not just focus on people's condition or symptoms, but on the person as a whole and safety within their environment.

Similarly, in a number of jurisdictions, quality of life, supporting people to fulfil their potential and thrive are often included as concept principles referring to wellbeing.

This is particularly evident in national standards, strategies and guidance documents for children and young people.^(15,16,17,18,19)

Again, safety, both in terms of providing safe care and support and safeguarding people from harm, is essential to a person's overall health and wellbeing. Safety as a principle was included in jurisdictions both in terms of preventing unnecessary harm caused by medical or social care interventions, and safeguarding people (especially children, older people and people with disabilities) against abuse by taking preventative actions.^(10,13,20) An example of this can be seen in *A healthier Wales: Our plan for Health and social care*⁽¹³⁾ which includes safety as one of its 10 design principles. It describes the principle of safety as "not only healthcare that does no harm, but enabling people to live safely within families and communities, safeguarding people from becoming at risk of abuse, neglect or other kinds of harm".

Responsiveness

Responsiveness emerged across multiple health and social care settings as responding to the needs of the person in care through the delivery of timely, consistent and appropriate care. Professionals should be open with the people they provide care and support to and communicate transparently, particularly when things go wrong. Familiarity with the people in a professional's care emerged as being an important facilitator of responsiveness, where the more that was known about a person improved the ability of professionals to care for them. Knowledge in general is key in facilitating responsiveness, and practices should be up to date, and informed by evidence at all times. Lack of skills, confidence and knowledge is seen as a barrier to carrying out responsive care, but continuous learning, positive motivation, and belief in one's own ability to carry out meaningful work facilitated this. These findings were consistent across multiple jurisdictions and health and social care contexts. As a principle, responsiveness should be ingrained in the culture of the organisation, but should also be applied in everything that the professional does in their daily work.

In Ireland, the principle of responsive services has been included as an underpinning principle in a number of existing national standards which outline the need to deliver responsive and consistent services based on evidence and good practice.^(21,22,23) In addition, under the principle of engagement, Sláintecare calls for the need to create a modern, responsive, integrated public health system.⁽²⁴⁾

In the UK, a number of pieces of adult social care legislation, including Care Act 2014 in England,⁽⁶⁾ the Social Services and Well-being (Wales) Act 2014,⁽²⁵⁾ and the Public Bodies (Joint Working) (Scotland) Act 2014⁽²⁶⁾ have emphasised the need for services to be designed and delivered to meet the needs of people using services as

opposed to needs of the service. This is reflected in national standards and guidance in these jurisdictions. For example, the Scottish Health and Social Care Standards⁽²⁷⁾ include responsive care and support as one of the five principles in its common set of principles that underpin all health and social services.

Finally, in relation to individual health and social care professionals being responsive to people's needs, international codes of practice for health and social care professionals consistently include principles related to meeting people's needs and the importance of professional duty and competence, integrity and honesty and communication.

Accountability

The principle of accountability in health and social care refers to the way in which health and social care organisations operate to achieve the best outcomes for people receiving care and support, and also the best outcomes for the people working in these organisations. Accountability, according to the literature, means that health and social care organisations are ultimately responsible for providing the highest standard of care and support to the people who need it, within the resources and facilities available to them. Accountability also means that there are transparent and robust structures in place so that staff understand their roles and responsibilities, and service users and staff alike know who to talk to when they have concerns about how care and support is being delivered.

The principle of accountability emerged in the literature, under the following five themes:

- Governance and culture
- Leadership
- Sustainability and value for money
- Working together
- Integration across settings

These themes were also reflected in the international review, where accountability was found to be a recurrent principle in health and social care national standards, guidance, patient charters, professional codes of conduct and strategy documents.

Person-centred care and support

Person-centred care and support emerged from the literature as being a central philosophy for delivery of care and support across multiple health and social care contexts. Person-centredness was found to underpin the four principles identified in this evidence review. In the context of a human rights-based approach, autonomy, empowerment and participation all contribute to a person-centred approach to care and support. A service that is safe and emphasises the overall wellbeing of people accessing care and support is person centred. A responsive service enables professionals to incorporate the context and background of each person in responding to their care and support needs provides person-centred care and support. Lastly, in the context of accountability, a person-centred approach needs to be ingrained in the organisational culture through models, frameworks and guidance. The literature highlighted that the person receiving care and support should be at the core of everything, and their best outcomes should always be of utmost consideration. This was consistent across multiple health and social care contexts.

The international review also found examples of person-centred care and support as an overall approach to care and support that takes into account the whole person and places them at the centre of planning and delivery of services.

The Health Foundation, in the UK, identified a framework for person-centred care which comprises four principles.⁽²⁸⁾ This is a clear example of where person-centred care is not viewed as a principle in itself. Instead, it outlines how any example of person-centred care, within any healthcare experience, will involve a combination of these principles. These principles can be seen to include the concepts of a human rights-based approach (dignity, compassion and respect), responsiveness (coordinated and personalised care and support), wellbeing (supporting people to develop their own strengths) and accountability (coordinated care).

Another example of where person-centred care is seen as an overall approach to care and support and the ultimate goal of all that services do can be seen the Welsh health and care standards.⁽²⁹⁾ These are set out according to seven themes which are intended to work together and collectively they describe how a service provides high-quality, safe and reliable care centred on the person.

Defining the draft principles

Based on the evidence review and consultation with key stakeholders, the Project Team developed the following working definitions to define each of the draft principles. In keeping with the international evidence and based on feedback from international experts, these descriptions are written from the point of view of people receiving health and social care services.

Human rights-based approach

My rights are promoted and protected by the health and social care services that I use. These include my right to autonomy, to be treated with dignity and respect, to make informed choices about my care and support, and my right to privacy. I am treated with kindness, consideration and compassion and I do not experience discrimination for any reason.

Safety and wellbeing

The services I use see my whole needs, not just the needs I am presenting with, and the care and support I receive helps to maintain and improve my overall health and emotional wellbeing and development. The health and social care services I use work in a way that promotes my safety and wellbeing and I am supported to live a whole and fulfilling life.

Responsiveness

The services I use work in partnership with me to meet my health and social care needs safely and effectively. I receive timely care and support that is tailored to suit my needs from skilled, experienced and trained staff, informed by the best available evidence and information. If I need care and support from more than one service or if I am leaving a service, they work together to ensure my needs are met in a holistic way.

Accountability

I know who is responsible for delivering my care and support and I have confidence and trust in the health and social care services I access. The services I use ensure that I receive safe, consistent, high-quality care and support and there is a culture of open communication, learning and reflection, and improvement. The services I use are well managed and everyone knows and understands their roles and responsibilities.

Next steps

The draft principles have been used in the development of the draft National Standards for Children's Social Services. A public consultation on these draft standards will commence in early 2021. This will be the first time the draft principles will be used and as such will be an opportunity to test them in practice. In addition to the content of the draft standards, feedback will be sought on the principles underpinning them during the consultation. Following this testing of the principles, and once feedback has been reviewed and incorporated as appropriate, the principles will be finalised and used for all future national standards for health and

social care services. The finalised principles will then be published on the HIQA website.

As previously outlined, this will not affect existing national standards, which will remain in place until such time as a decision is made, in line with HIQA's prioritisation process, to review and update them. Any such decision to review or update existing standards will be informed by consultation with stakeholders.

The development of evidence-based principles provides a unique opportunity to incorporate consistent and meaningful principles throughout legislation, professional standards and health and social care standards. This will optimise the consistency and integration of health and social care systems and processes with a common vision focused on improving the experience of and outcomes for, people receiving care and support.

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