



**Health
Information
and Quality
Authority**

An tÚdarás Um Fhaisnéis
agus Cáilíocht Sláinte

**Background document to
inform the development of
guidance on a human rights-
based approach to care and
support in health and social
care settings**

June 2019

Safeguarding
I R E L A N D 

Promoting the rights of vulnerable adults

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 and Youth Affairs, 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 Office of 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.

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Executive summary

Human rights are the basic rights and freedoms that all people should enjoy. A human rights-based approach to health and social care is about ensuring that human rights are protected in practice and embedded in the culture of a service. A human rights-based approach to health and social care involves empowering people to know and claim their rights. It also involves increasing the ability and accountability of staff working in health and social care services to respect, protect and fulfil the human rights of people using services.

Although human rights are enshrined in legislation nationally and internationally, it has been recognised that there is a widespread lack of knowledge and understanding of the application of human rights principles among people using services, health and social care practitioners and within organisations. This has been recognised by the State's regulators — the Health Information and Quality Authority (HIQA) and the Mental Health Commission — through inspections of health and social care services.^(1,2) Furthermore, findings from the literature indicate that health and social care practitioners may lack clarity on how to incorporate human rights principles, laws and regulations into their practice.⁽³⁾ Increasing knowledge and understanding of human rights empowers health and social care practitioners to protect human rights, develop the skills to defend human rights, and integrate the principles of human rights into everyday practice.⁽⁴⁾

A human rights-based approach to care and support already features in a number of existing standards developed by HIQA, for example:

- *National Standards for Safer Better Healthcare*⁽⁵⁾
- *National Standards for Residential Care Settings for Older People in Ireland*⁽⁶⁾
- *National Standards for Residential Services for Children and Adults with Disabilities*⁽⁷⁾
- *National Standards for Children's Residential Centres*⁽⁸⁾
- *Draft National Standards for Adult Safeguarding.*

In 2018, HIQA and the Mental Health Commission jointly developed draft National Standards for Adult Safeguarding. Once approved by the Minister for Health, they will apply to all health and social care services, including mental health services, in Ireland. Safeguarding Ireland (formerly the National Safeguarding Committee) has determined that a key action should be promoting awareness and providing training to management and practitioners on delivering care in a way that promotes human rights.

One of HIQA's roles is to promote safety and quality in the provision of health and social care services for the benefit and welfare of the public; promoting a human rights-based approach to care and support is central to this. HIQA seeks to support the development of a culture where a human rights-based approach is embedded in practice, rather than being viewed as a separate activity. Using this approach in health and social care settings can improve the outcomes for people using services and practitioners alike, and aid the delivery of better-quality, more person-centred care* and support.

HIQA is developing an educational guidance document for health and social care service providers on a human rights-based approach to care and support. This guidance will expand on national standards to support a consistent interpretation of a human rights-based approach.

The guidance, which is part-funded by the Irish Human Rights and Equality Commission (IHREC) under the Human Rights and Equality Grant Scheme 2017 (applied for by HIQA on behalf of Safeguarding Ireland), will be a practical and accessible resource, designed to support practitioners across a wide range of health and social care services. It aims to help practitioners understand what a human rights-based approach to care and support is, and to ensure that the human rights of people using services remain at the centre of the services they use.

The guidance will also be a useful tool for people using services, their families and advocates. The guidance document will be developed through a formal process, which will include a thorough review of evidence in combination with extensive engagement with key stakeholders.

This background document was developed as part of HIQA's guidance development process which consists of:

- An **overview of a human rights-based approach to health and social care** – this includes an overview of key definitions and principles relating to a human rights-based approach to health and social care, including the FREDA principles (Fairness, Respect, Equality, Dignity, Autonomy).
- An **overview of relevant legislation** – this includes an overview of relevant conventions and laws relating to human rights in health and social care. It pays particular attention to changes in Irish law which relate to a human rights-based approach to care and support, including the ratification of the

* While person-centred care can be a feature of a human rights-based approach, it is not required by law. A human rights-based approach is underpinned by a legal framework reflecting the binding international human rights treaties which states have agreed to uphold.⁽⁹⁾

United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and the introduction of the Assisted Decision-Making (Capacity) Act 2015 in Ireland. This overview describes the context in which the guidance is being developed.

- An **international review** examining the implementation of a human rights-based approach in England, Scotland, Iceland and the Netherlands. This is based on desktop review of legislation, key policy documents and resource materials that are used within these jurisdictions to inform a human rights-based approach to care in their health and social care services. This review is also informed by teleconference calls held with key personnel from these jurisdictions.
- An **evidence synthesis** – this includes a detailed synthesis and review of existing literature and evidence to inform the development of the guidance. This review ensures that the work is informed by quality evidence and reflects international best practice. The evidence synthesis process has two phases: Phase 1 involved the completion of a scoping review and Phase 2 consisted of a systematic search, literature review and critical appraisal of national and international literature relating to human rights-based care and support as described under the FREDA principles.[†]

Information and findings from the international review and evidence synthesis will be used to inform the development of the guidance to support a human rights-based approach to care and support in health and social care settings for adults.

Key findings

Key findings from the international review and evidence synthesis include the following:

- Central to a human rights-based approach to care and support is ensuring that people who use services are placed at the heart of service development and provision. The findings from the evidence synthesis and international review indicated that a paternalistic approach to care still exists. However, internationally services are moving away from such an approach towards a person-centred approach that promotes the empowerment and participation of people who use services in their own care, support and treatment plans. Empowerment can be fostered by clear and appropriate communication between service providers and people using services.

[†] The five FREDA principles are Fairness, Respect, Equality, Dignity, Autonomy. Further details can be found in Section 1.3.

- Findings from the international review in particular indicated the importance of human rights being embedded in legislation and policy at central and local government level. Work in this area in Scotland and the Netherlands illustrated the benefit of creating a National Action Plan on human rights in order to progress a human rights agenda. It is important to ensure politicians and policymakers have a clear knowledge of human rights and the application of human rights in terms of both policy development and in delivering health and social care services.
- Additionally, findings from the international review emphasised the important role that human rights organisations can play in the development of resources, tools, training and engagement to help services understand and implement a human rights-based approach in their work. Partnering with health and social care services, as demonstrated in particular by the work of the British Institute of Human Rights, in developing these resources can help to increase their relevance and accessibility to front-line staff.
- Communication is an integral part of working with people using services. The findings from the evidence synthesis highlighted the importance of providing people with adequate and accessible information on their health or personal status, to ensure they are fully aware of all their options regarding their care and support. It also highlighted the importance of ensuring that any disclosure of personal information about a person's health or personal status respects their right to a private life.
- Findings from the evidence emphasised the importance of ensuring access to appropriate health and social care services according to a person's needs. They also indicated the need for people using services to receive access to standard treatments on an equal basis with the general population.
- The evidence also underlined the importance of supporting people to exercise autonomy in decisions relating to their care and support. In addition, the findings showed the importance of decision-making processes based on the human rights of the person using services. By applying a human rights-based approach to decision-making, health and social care practitioners can weigh up the rights of the person using a service while taking into account the risks which could affect the person's or other people's safety or wellbeing.
- The findings from the evidence showed that clear processes are necessary in a service to ensure fair and consistent decision-making about care, support and treatment. This relates to the process of informed consent and ensures that the person using the service is fully informed and actively involved in the process. Each service must ensure that it has such a process in place.

- The importance of presuming an individual's capacity unless specific criteria are met is highlighted in literature. When a person is deemed not to have the capacity to make decisions regarding their care and support, any intervention decided on by a health or social care practitioner must be justifiable and proportionate, weighing up the risk to others and the risk to the person's own wellbeing and safety. Capacity must be continuously reviewed as it can fluctuate.
- The evidence demonstrated the importance of exploring options other than restraint or restrictive practices when a person using a service displays disruptive or challenging behaviour. This includes ensuring that, if used, restrictive practices are proportionate to the behaviour they are being used to restrict; are the least restrictive; applied for the shortest possible time; and subject to a timely review.
- The findings underlined the need for human rights to be embedded in service provision rather than being seen as a separate concern. They also highlighted the importance of services developing policies and models of care and support that have human rights at their core to ensure an organisation-wide approach to implementation. Such policies and models of care can also help to prevent violations of human rights in services. Evident from the evidence synthesis was a lack of knowledge within services of what constitutes a human rights-based approach. It is necessary to educate, train and support staff on how to embed this approach in their everyday work. It is also important to involve people using services in the development of services.
- Also emphasised was the need for health and social care providers to understand the barriers facing people using services and to make sure that they directly engage with people to understand their needs and views. This means acknowledging and accommodating difference rather than treating everyone the same. It is about recognising that, although everyone has the same human rights, different groups may have additional needs. It is important for services to provide additional supports for these groups to ensure their needs are met.
- The international review also highlighted the importance of developing indicators to monitor human rights. At a local level this included the development of human rights and equality impact assessment tools for organisations to reflect on their service provision in relation to human rights.

1. Introduction

1.1 Overview

Human rights are protected under the Universal Declaration of Human Rights and in the European Convention on Human Rights.^(10,11) They are the fundamental rights that every person is born with. A human rights-based approach to care and support is the process by which human rights are protected in clinical and organisational practice, and embedded within the culture of an organisation.⁽¹²⁾ This approach considers a violation of a person's human rights to be detrimental to their health.⁽¹²⁾ Using a human rights-based approach can achieve better outcomes for people using services and practitioners alike and deliver better-quality, person-centred care[‡] and support.⁽¹²⁾ Increasing knowledge and understanding of human rights empowers health and social care practitioners to:

- protect human rights
- develop respect for human rights
- develop the skills needed to defend human rights
- integrate the principles of human rights into everyday practice
- encourage respect and tolerance.⁽⁴⁾

In recent years in Ireland, with the introduction of national and international human rights legislation, there has been a clear shift in policy and practice to a focus on human rights, empowerment and choice. Human rights are enshrined within the codes and guides of conduct and ethics of different professional bodies including medicine, social work and nursing.^(13,14,15) For example, Principle 1 (respect for the dignity of the person) of the Nursing and Midwifery Board of Ireland's (NMBI) Code of Professional Conduct and Ethics, is drawn directly from the Universal Declaration of Human Rights.⁽¹³⁾ Despite practitioners' obligations to adhere to their professional codes of conduct, there remains a lack of awareness of how to incorporate ethical and human rights norms into practice. This has been recognised by the State's regulators (HIQA and the Mental Health Commission) through inspections in health and social care services,^(1,2) and more recently in Ireland's submissions made to the 61st session of the UN Committee Against Torture 2017,⁽¹⁶⁾ which shows that national and local policy appears to enable practices inconsistent with a human rights-based approach to care and support. Internationally, the literature suggests

[‡] While person-centred care can be a feature of a human rights-based approach, it is not required by law. A human rights-based approach is underpinned by a legal framework reflecting the binding international human rights treaties which states have agreed to uphold.⁽⁹⁾

that the lack of awareness could be attributed to an existing paternalistic approach to providing care and support, which holds that the practitioner knows best.^(17,18,19) Furthermore, it suggests that poor pay, poor working conditions and a lack of support can contribute to high staff turnover rates and tasks being completed in a limited time period. These limitations carry inherent human rights risks for people using services. The literature clearly points to the need for information and staff training in a human rights-based approach.^(18,20,21,22) As well as improving outcomes for people using services, human rights training can also enable practitioners to identify situations where their own human rights are at risk.⁽²³⁾

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. The Health Act 2007⁽²⁴⁾ states that one of HIQA's objectives is to promote safety and quality in the provision of health and personal social services for the benefit of the health and welfare of the public. As well as setting standards for these services,⁽²⁵⁾ one of the ways HIQA promotes safety and quality in service provision is by developing guidance to support service providers and staff in understanding and implementing national standards, regulations and other requirements. HIQA is currently developing guidance to support a human rights-based approach in health and social care services for adults. The guidance will be a practical and accessible document, designed to support practitioners across the wide range of health and social care services to understand what a human rights-based approach is and identify ways to ensure the rights and best interests of people using services remain at the centre of service provision. It seeks to support the development of a culture in which a human rights-based approach is embedded into practice.

1.2 National standards developed by HIQA and how they relate to human rights

HIQA's role is to develop standards, inspect and review health and social care services and support informed decisions on how services are delivered. High-level reference is made to a human rights-based approach to care and support in a number of national standards developed by HIQA. Within existing national standards,^(6,26,27) emphasis is placed on protecting and promoting people's rights and respecting their autonomy, privacy, dignity, values, preferences and diversity. These national standards emphasise the importance of actively involving people using services in their own care and promote a culture of kindness, consideration and respect. The relationship between specific human rights as set out under the European Convention on Human Rights⁽¹¹⁾ and some of the individual national standards – for example, *National Standards for Safer Better Healthcare*,⁽²⁶⁾ *National Standards for Safer Better Maternity Services*,⁽²⁷⁾ *National Standards for Residential*

Services for Children and Adults with Disabilities⁽⁷⁾ and *National Standards for Residential Care Settings for Older People Ireland*⁽⁶⁾ – is outlined in Appendix 1.

In relation to the *National Standards for Safer Better Healthcare*,⁽²⁶⁾ key standards that promote a human rights-based approach in health and social care services include:

- 'Service providers ensure all reasonable measures are taken to protect service users from abuse.' (Standard 3.4)
- 'Service users experience healthcare which respects their diversity and protects their rights.' (Standard 1.3)
- 'Service users are enabled to participate in making informed decisions about their care.' (Standard 1.4)
- 'Service users' informed consent to care and treatment is obtained in accordance with legislation and best available evidence.' (Standard 1.5)
- 'Service users' dignity, privacy and autonomy are respected and promoted.' (Standard 1.6)
- 'Service providers promote a culture of kindness, consideration and respect.' (Standard 1.7)⁽²⁶⁾

In 2018, HIQA and the Mental Health Commission jointly developed draft National Standards for Adult Safeguarding. Once approved by the Minister for Health, they will apply to all health and social care services in Ireland, including mental health services. HIQA aims to support services to safeguard people and improve the safety and quality of health and social care services. Safeguarding means putting measures in place to promote people's human rights, health and wellbeing, and empowering people to protect themselves.⁽²⁸⁾ In examining requirements for promoting best practice in the safeguarding of vulnerable adults, Safeguarding Ireland (formerly the National Safeguarding Committee) determined that a key action should be promoting awareness and providing training to management and practitioners on how to deliver care and support in a way that promotes and protects the rights of people using services.

The information outlined in the human rights-based care guidance will help to promote awareness of, and support services to implement, a human rights-based approach to care and support. It will also support services to understand and implement national standards. Finally, it will ensure a consistent interpretation of this kind of approach across health and social care services.

1.3 The FREDA Principles

Researchers have argued that too much emphasis has been placed on the legalistic nature of human rights rather than their underlying values.⁽²⁹⁾ Some useful, non-legalistic approaches to human rights for health and social care include the PANEL principles and the FREDA principles.

The PANEL principles⁽³⁰⁾ are one way of breaking down what a human rights-based approach means in practice. PANEL stands for Participation, Accountability, Non-discrimination and equality, Empowerment, and Legality.

The FREDA principles of Fairness, Respect, Equality, Dignity and Autonomy are the basics of good care and form part of what practitioners already do on a daily basis.⁽¹²⁾ While it is useful to consider each principle individually, it should be understood that they are interdependent. A human rights-based approach involves all five principles. These principles are used to inform decisions, not determine them.⁽¹²⁾ All of the principles must inform each decision, but the weight given to each principle in reaching a conclusion will depend on the issues under consideration.⁽¹²⁾ It may be the case that in making some decisions, a greater weight should be given to some of the principles over others.⁽¹²⁾

The FREDA principles and similar concepts emerged clearly as themes in the literature and have been used to structure Section 5 of this document.^(31,32)

Figure 1 below provides definitions[§] for each of the principles as used by the Project Team for the purpose of this background document.

[§] These definitions have been adapted from a range of sources, including Curtice and Exworthy (2010), the Care Quality Commission (2014), the Health Information and Quality Authority (2016) and the Irish Human Rights and Equality Commission (2015).

Figure 1: The FREDA Principles



1.4 How the guidance will be developed

The guidance will be informed by the evidence presented in this document, which has been developed in line with HIQA's evidence synthesis process.⁽³³⁾ Extensive stakeholder engagement will also be undertaken to inform the draft guidance. HIQA has convened an Advisory Group comprised of a diverse range of interested and informed parties, including representatives from support and advocacy groups, regulatory bodies, professional representative organisations, the HSE and the Department of Health. The function of the group is to advise HIQA, support consultation and information exchange, and advise on any further steps.

HIQA also held a public scoping consultation in October 2018 which involved consulting with people who have experience of services. The consultation gave people an opportunity to identify the key areas that this guidance should address and to provide examples of good practice. In addition, as part of its international review, HIQA engaged with key stakeholders in international jurisdictions.**

HIQA has also organised focus groups with front-line staff and management, people using services and advocates to obtain expert opinions on what should be included in the guidance and how it can be implemented in practice.

In addition to this, HIQA will undertake a public consultation process in 2019 for members of the public and all interested parties to submit their views on the draft guidance. The approved guidance will be made publicly available on the HIQA website.

1.5 Structure of this report

This document sets out the findings of the review undertaken to inform the development of the draft guidance to support a human rights-based approach in health and social care services. It includes:

- Section 2: Overview of Relevant Legislation
- Section 3: International Review
- Section 4: Evidence Synthesis Methodology
- Section 5: Evidence Synthesis Findings
- Section 6: Summary, Conclusion and Next Steps

** See Appendix 2 for the names and affiliations of the experts with whom HIQA engaged.

2. Overview of Relevant Legislation

This section provides a summary of relevant conventions and legislation relating to human rights in health and social care, paying particular attention to Irish laws which relate to a human rights-based approach to care and support. This overview describes the context in which the guidance is being developed.

A right is an entitlement that an individual can legally or morally claim, and a human right is a right which a human being possesses by virtue of the fact that he or she is a human being.⁽³⁴⁾ Human rights are the rights that all human beings should have regardless of nationality, place of residence, sex, national or ethnic origin, colour, religion, language or any other status.⁽²⁸⁾ International law, including treaties, contain the provisions which give human rights legal effect.⁽³⁵⁾ Human rights are found in international (mainly United Nations), regional (European) treaties, or in national constitutions and national legislation.⁽³⁵⁾ Under the European Convention on Human Rights (ECHR),⁽¹¹⁾ everyone has a number of rights. The European Convention on Human Rights Act 2003⁽³⁶⁾ is an act of the Oireachtas (Irish parliament), which further implemented the ECHR⁽¹¹⁾ in Irish law (see Section 2.3.2).

2.1 The Universal Declaration of Human Rights

The 1948 Universal Declaration of Human Rights (UDHR)⁽¹⁰⁾ is a milestone document in the history of human rights. It set out, for the first time, fundamental human rights to be universally protected.^{††} The European Convention on Human Rights (ECHR)⁽¹¹⁾ is directly derived from the UDHR.

2.2 The European Convention on Human Rights

The ECHR⁽¹¹⁾ is the basis of the European human rights system. It was drafted by the Council of Europe^{††} in 1950, after the Second World War, and has been in force since 1953.⁽³⁵⁾ It was the first regional treaty designed to protect human rights, democracy and the rule of law.⁽³⁵⁾ The main purpose of the ECHR was to limit a state's interference with the rights of citizens.⁽³⁷⁾ All 47 Council of Europe member states have signed the ECHR.⁽³⁵⁾ The ECHR is an international treaty to protect human rights and political freedoms in Europe. States which have signed up to the

^{††} The UDHR is not a treaty, so it does not directly create legal obligations for countries. It is an expression of fundamental values and agreed-upon standards, but is not legally binding. Conventions are stronger than declarations because they are legally binding for governments that have signed them. However, the UDHR has had a profound influence on the development of international human rights law.

^{††} The Council of Europe focuses on human rights and the rule of law across its 47 Member States, which account for almost the entire continent of Europe. Ireland joined the Council of Europe in 1949. The primary human rights text of the Council of Europe is the ECHR. The rights set out in the ECHR are enforced by the European Court of Human Rights, which is located in Strasbourg.⁽³⁵⁾

ECHR are bound by international law to secure for everyone within their jurisdiction the rights and freedoms set out in it. Human rights defined under the ECHR include:⁽¹¹⁾

- Article 1: Obligation to respect Human Rights
- Article 2: Right to life
- Article 3: Prohibition of torture
- Article 4: Prohibition of slavery and forced labour
- Article 5: Right to liberty and security
- Article 6: Right to a fair trial
- Article 7: No punishment without law
- Article 8: Right to respect for private and family life
- Article 9: Freedom of thought, conscience and religion
- Article 10: Freedom of expression
- Article 11: Freedom of assembly and association
- Article 12: Right to marry
- Article 14: Prohibition of discrimination.^{§§}

It has been argued that Article 8 is perhaps the most influential of the articles which directly affect the provision of healthcare.⁽³⁷⁾ It adds statutory force to the capable adult's right to self-determination, a right that can be exercised in defiance of the right to life (Article 2) and the right to freedom from inhuman and degrading treatment (Article 3).⁽³⁷⁾

2.3 Relevant legislation in an Irish context

A number of existing and draft pieces of legislation are relevant to the provision of a human rights-based approach to care and support in Ireland. These include:

- The Irish Constitution
- The European Convention on Human Rights Act 2003
- The Equal Status Acts 2000-2015

^{§§} In respect of these rights and freedoms.

- The Health Act 2007
- The Mental Health Act, 2001
- The Irish Human Rights and Equality Commission Act 2014 (IHREC Act 2014)
- The UN Convention on the Rights of Persons with Disabilities (2006)
- The Assisted Decision-Making (Capacity) Act 2015

A high-level summary of these laws in the context of human rights is outlined in the following subsections.

2.3.1 The Irish Constitution

The Irish Constitution is the fundamental legal document that sets out how Ireland should be governed and the rights of Irish citizens. It was signed into law in 1937. All legislation passed by the Irish Government must be compatible with the Irish Constitution. The Constitution can only be changed by a referendum of the people. The Constitution sets out a number of fundamental rights. These include:⁽³⁵⁾

- right to life
- equality before the law
- right to a fair trial
- right to liberty
- right to freedom of expression, assembly and association
- protection of the family.⁽³⁵⁾

In addition, the courts have interpreted the Constitution as including certain other human rights. These are referred to as unremunerated rights (not explicitly set out in the Constitution but recognised by the courts), and include:⁽³⁵⁾

- right to bodily integrity
- right to freedom from torture, inhuman or degrading treatment or punishment
- right to work and earn a livelihood
- right to privacy.⁽³⁵⁾

2.3.2 European Convention on Human Rights Act 2003

Although Ireland was one of the original countries to sign up to the ECHR in 1950, the Convention was not brought directly into Irish law until 2003.⁽³⁵⁾ Up to that point, any individuals in Ireland who felt their human rights had been breached had to seek redress in the European Court of Human Rights in Strasbourg, a process that took many years to complete.⁽³⁷⁾ The European Convention on Human Rights Act (ECHR Act) 2003⁽³⁶⁾ removed that process by incorporating the main provisions of the ECHR and making them enforceable in Irish law, allowing these rights to be considered by Irish courts. The ECHR Act 2003 means that, subject to certain conditions, Irish courts are obliged to interpret any law in a way that is compatible with the ECHR.⁽³⁵⁾ If this is not possible, the court may find that Irish legislation or practice is not in line with the ECHR. In this case, it can either find that the State has breached its statutory duty or it can make a Declaration of Incompatibility,^{***} which must then be considered by the Irish Government. Whenever a Declaration of Incompatibility is sought in legal proceedings, the Attorney General and the Irish Human Rights and Equality Commission (IHREC) are formally notified.⁽³⁵⁾ The Irish Constitution has priority over the ECHR Act (in cases where there is any uncertainty) and, if the two conflict, the Irish Constitution prevails.⁽³⁵⁾

2.3.3 Equal Status Acts 2000-2015

The Equal Status Acts 2000-2015 ('the Acts')⁺⁺⁺ outline ten grounds of discrimination, which are:

- age
- civil status
- disability
- family status

^{***} Where existing legislation conflicts with provisions of the ECHR or leads to decisions by public bodies that undermine ECHR rights, the ECHR Act gives the courts power to issue a declaration that the legislation at issue was incompatible with the ECHR. This leaves it up to the Irish Government to change the law to bring it into line with the ECHR.

⁺⁺⁺ The Equal Status Acts 2000-2015 includes:

- Equal Status Act, 2000
- Equality Act, 2004
- Equal Status (Amendment) Act 2012
- Equality (Miscellaneous Provisions) Act 2015.

- gender
- being in receipt of rent supplement, housing assistance, or social welfare payments
- membership of the Traveller community
- race, colour or nationality
- religion
- sexual orientation.

Subject to certain exemptions, the Acts prohibit discrimination in access to and use of goods and services, including indirect discrimination and discrimination by association, sexual harassment and harassment, and victimisation. The Acts allow positive action to promote equality for disadvantaged persons or to cater for the special needs of persons. Discriminatory advertising is also prohibited. It is prohibited to publish, display or cause to be published or displayed, an advertisement which indicates an intention to discriminate, harass or sexually harass or might reasonably be understood as indicating such an intention. In addition, the Acts require that service providers do whatever is reasonable to accommodate a person with a disability whose disability prevents them from accessing that service.⁽¹¹⁾

Services provided by the State (such as the HSE, local authorities, and so on) are covered by the Acts, but there are some exemptions. The main exemption is that anything required to be done by another Irish law or EU law cannot be regarded as discrimination under the Equal Status Acts. For example, it is not discrimination to refuse a social welfare payment to a person if that person is excluded from entitlement to the payment or benefit under social welfare law. There are also specific exemptions on nationality grounds in relation to the treatment by public authorities of certain^{***} foreign nationals.⁽¹¹⁾

2.3.4 Health Act 2007

The Health Act 2007⁽²⁴⁾ provides for the establishment of HIQA to reform the regulation of health and social care services in Ireland. In addition to this, under the Health Act 2007, HIQA has statutory responsibility for setting standards for health and social care services.

^{***} Public authorities can treat certain non-nationals differently, on the basis of their nationality, who are outside the State or unlawfully present in it (for the purposes of the Immigration Act 2004) or in accordance with any provision or condition made by or under any enactment and arising from his or her entry to or residence in the State.

The Health Act 2007 (Care and Support of Residents in Designated Centres for Persons (Children and Adults) with Disabilities) Regulation 2013⁽³⁸⁾ states a requirement for registered providers to notify HIQA of any adverse events, including allegations of abuse or suspected abuse of residents. The regulations for older people as set out in the Health Act 2007 (Care and Welfare of Residents in Designated Centres for Older People) Regulations 2013⁽³⁹⁾ also require registered providers to implement policies and procedures for the prevention, protection and response to abuse, and require that any incidents be reported to HIQA.

2.3.5 Mental Health Act, 2001

The Mental Health Act, 2001⁽⁴⁰⁾ establishes the Mental Health Commission and its functions as the regulator of mental health services in Ireland. The Act addresses two main requirements in the provision of mental health care in a modern society:

- the establishment of a legislative framework within which persons with a 'mental disorder' (as defined in the Mental Health Act, 2001) may be admitted, detained and treated involuntarily in approved centres
- the promotion and maintenance of quality standards of care and treatment that are regularly inspected and properly regulated.

In Ireland, the Mental Health Act, 2001 addresses certain human rights issues in relation to individuals with mental disorders, primarily related to involuntary treatment and assuring standards across services.⁽³⁴⁾ While the legislation poses challenges to mental health services, there is significant agreement that it improves protection of the right to liberty among individuals with mental disorders.⁽³⁴⁾ It also increases Ireland's adherence to international human rights standards in areas of traditional concern in mental health care, especially involuntary admission and treatment.⁽³⁴⁾ Most people receiving treatment in an approved centre^{§§§} do so by choice. However, people with mental disorders are sometimes admitted and treated as involuntary patients. The Act⁽⁴⁰⁾ provides two methods for detaining a patient who has a mental disorder:

- admission by a consultant psychiatrist on the recommendation of a registered medical practitioner
- 're-grading' a voluntary patient to an involuntary patient following review by two consultant psychiatrists.

^{§§§} A 'centre' is defined in the Mental Health Act, 2001 as "a hospital or other in-patient facility for the care and treatment of persons suffering from mental illness or mental disorder" and an 'approved centre' is a centre that is registered by the Mental Health Commission.

Under the Act, a person who is involuntarily admitted to an approved centre has their case independently reviewed by a mental health tribunal within 21 days of their admission or renewal order.⁽⁴¹⁾ Every tribunal is comprised of a chairperson, consultant psychiatrist and layperson.⁽⁴¹⁾ A patient has the right to attend their own tribunal and adults receive free legal representation for their hearing during their period of involuntary detention.⁽⁴¹⁾

In May 2017, the High Court ruled that the involuntary detention of a patient on a 12-month renewal order under the Mental Health Act, 2001 was incompatible with the ECHR. This provision of detention was previously permissible under Section 15 of the Mental Health Act, 2001.⁽⁴²⁾ This led to emergency legislation to amend the Mental Health Act, 2001 to allow for the removal of the section which provides for patients to be involuntarily detained under renewal orders. The Mental Health (Amendment) Act 2018 was signed into law in Ireland in July 2018.⁽⁴³⁾

2.3.6 Irish Human Rights and Equality Commission Act 2014

The Irish Human Rights and Equality Commission Act 2014 (IHREC Act 2014)⁽⁴⁴⁾ provides for the establishment of the Irish Human Rights and Equality Commission. The Commission has a broad statutory remit in relation to the protection and promotion of human rights and equality under the IHREC Act 2014. Section 10(1) of the IHREC Act 2014 sets out the overall functions of the Commission as follows:⁽⁴⁵⁾

- to protect and promote human rights and equality
- to encourage the development of a culture of respect for human rights, equality, and intercultural understanding in the State
- to promote understanding and awareness of the importance of human rights and equality in the State
- to encourage good practice in intercultural relations, to promote tolerance and acceptance of diversity in the State and respect for the freedom and dignity of each person
- to work towards the elimination of human rights abuses, discrimination and prohibited conduct.⁽⁴⁵⁾

2.3.7 United Nations Convention on the Rights of Persons with Disabilities (2006)

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)⁽⁴⁶⁾ and its Optional Protocol^{****} was adopted on 13 December 2006 at the United Nations Headquarters in New York, and was opened for signature on 30 March 2007. The purpose of the UNCRPD is 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. Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which may hinder their full and effective participation in society on an equal basis with others.⁽⁴⁶⁾ In March 2018, the Irish Government passed a motion to ratify the UNCRPD. The UNCRPD is closely related to a broader human rights agenda, for example:

- being involved in advocacy endeavours striving for access to justice for people with disabilities (Article 13 UNCRPD)
- equal recognition before the law (Article 12 UNCRPD)
- freedom of expression and opinion, and access to information (Article 21 UNCRPD), work and employment (Article 27 UNCRPD)
- participation in political and public life (Article 29 UNCRPD).⁽⁴⁷⁾

2.3.8 The Assisted Decision-Making (Capacity) Act 2015

The Assisted Decision-Making (Capacity) Act 2015 (‘the 2015 Act’)⁽⁴⁸⁾ provides a modern statutory framework to support decision-making by adults whose capacity is in question or may be called into question. It reforms Ireland’s existing capacity legislation, some of which had been in place since the 19th century.

The 2015 Act allows adults to enter into legally binding arrangements, to be assisted and supported in making decisions about their personal welfare and their property and affairs. The 2015 Act also provides for advanced planning by adults who have capacity, by way of expanded enduring powers of attorney and Advance Healthcare Directives.

**** The Optional Protocol provides for two types of procedure: a) Individual communications procedure: this allows individuals or groups of individuals to take a complaint to the Committee on the Rights of Persons with Disabilities (CRPD Committee) when one or more of their CRPD rights has been breached. b) Inquiry procedure: under this procedure, individuals or organisations can bring a complaint to the CRPD Committee alleging “grave or systematic violations by a State Party of rights set forth in the Convention”.

The 2015 Act establishes a statutory presumption of capacity and sets out a functional test for the assessment of a person's capacity where concern exists. A person is determined to lack capacity to make a decision if they are unable to:

- understand the information relevant to the decision
- retain that information long enough to make a voluntary choice
- use or weigh that information as part of the process of making the decision
- communicate their decision in whatever way they communicate (this may include using any assistive measures, for example, talking, writing, using sign language, assistive technology or any other means).

Under the provisions of the 2015 Act,⁺⁺⁺ the Mental Health Commission's remit has been extended to include the establishment of the Decision Support Service (DSS). The DSS will support decision-making by and for adults with capacity difficulties and will regulate individuals who are providing those supports.

At the time of writing this report, a number of provisions of the 2015 Act have been commenced which have enabled the establishment of the DSS, the recruitment of the Director of the DSS, and the convening of working groups to prepare a suite of draft codes of practice.

Legislative clarity on the issue of the deprivation of liberty in residential facilities for older people, people with a disability, and people with mental health issues is required in order for Ireland to satisfy the requirements of the UNCRPD⁽⁴⁶⁾ and align with obligations under the ECHR.⁽¹¹⁾ In 2017, draft Heads of Bill were prepared by the Department of Health with the assistance of the Department of Justice and Equality. It is anticipated that the bill will amend the 2015 Act⁽⁴⁸⁾ to introduce Part 13, setting out 'Deprivation of Liberty Safeguards'. Existing legislation does not provide a procedure for admitting persons who lack capacity to consent to facilities in which they will be under continuous supervision and control, and not free to leave. There are no legal safeguards to ensure that such persons are not unlawfully deprived of their liberty.⁽⁴⁸⁾ At the time of writing this report, it is understood that revised draft Heads of Bill are in progress.

2.3.9 Deficiencies in human rights legislation and policy in Ireland

Under the Health Act 1970,⁽⁴⁹⁾ it is the right of all people who live in Ireland to have access to health services. In addition, under the Mental Health Act 2001, a person

⁺⁺⁺ At the time of writing, the Assisted Decision-Making (Capacity) Act 2015 is not fully commenced.

has the right to receive good-quality mental health care.⁽⁴⁰⁾ The Public Sector Equality and Human Rights Duty places a legal obligation on all public bodies,^{****} including State departments, to promote equality, prevent discrimination and protect the human rights of their employees, customers, service users and everyone affected by their policies and plans.⁽⁴⁴⁾ Despite the legislation in place, Ireland has been criticised in a Council of Europe report for failing to guarantee the right of access to healthcare. The report, by the European Committee of Social Rights (ECSR), follows an assessment of 33 states regarding their compliance with the European Social Charter's requirements on health, social security and social protection services. The report notes that Ireland has not established that the right of access to healthcare is guaranteed in practice, and it has not been established that there is an effective and equal access to social services.⁽⁵⁰⁾

Ireland signed the Optional Protocol to the Convention Against Torture (OPCAT) on 2 October 2007, but at the time of writing this report it has yet to ratify this instrument. OPCAT is an international human rights treaty which assists states in preventing torture and other forms of ill-treatment in places of detention. Ratification would oblige the State to have domestic systems of inspection and oversight that are entirely independent of government. The State would also have to facilitate inspection visits by the UN Sub-committee on the Prevention of Torture.

This section highlights that in recent years, Ireland has taken a number of positive steps towards drafting and implementing legislation that supports the provision of a human rights-based approach to care and support including the ECHR Act (2003), the IHREC Act 2014, the UNCRPD (2006) and the Assisted Decision-Making (Capacity) Act 2015. However, deficits in human rights continue to be recognised in health and social care services and within Irish legislation. It is important that Ireland continues to introduce, ratify and implement human rights legislation for the benefit of the health and welfare of people using health and social care services.

3. International Review

3.1 A human rights-based approach to care and support: a review of international jurisdictions

This review provides an overview of human rights-based approaches across four international jurisdictions:

^{****} A public body under Section 2 of the Irish Human Rights and Equality Commission Act 2014 includes: a Department of State; a local authority; the Health Service Executive; a university or institute of technology; an education and training board; any other person, body or organisation established under statute; a company wholly or partly financed by or on behalf of a Government Minister and a company where the majority shares are held by or on behalf of a Government Minister.

- England
- Scotland
- The Netherlands
- Iceland

The review examines key areas in relation to each of these international jurisdictions; this includes their legal framework for integrating human rights within health and social care services and the key organisations involved in supporting and monitoring the protection and promotion of human rights within services. The review also includes standards, guidelines, supporting tools and resources that have been developed in each of these jurisdictions which support health and social care practitioners to understand and implement a human rights-based approach in their day-to-day work.

3.1.1 Methodology

The four jurisdictions were chosen following feedback from the scoping consultation, findings from the evidence synthesis and input from key stakeholders. A further desktop review involving web-based searches of relevant literature and websites identified a number of key organisations and experts to contact and engage with.

As part of the international review, teleconference calls were held with experts^{§§§§} in England, Scotland, Iceland and the Netherlands between February and April 2019. The experts were primarily leaders in human rights and inspectorate organisations. They provided key information on the current human rights climate within their jurisdictions and they assisted with providing resource materials relevant to the topic. Findings and 'lessons learned' in applying a human rights-based approach from their respective jurisdictions were discussed.

3.2 England

This section provides an overview of relevant human rights legislation, standards, guidelines and supporting tools and resources in place in England.

3.2.1 Legislation

Much like other European countries, England's national legal framework for human rights is informed by the European Convention on Human Rights. This section

^{§§§§} See Appendix 2 for the names and affiliations of the experts with whom HIQA engaged.

outlines current legislation that relates to human rights and a human rights-based approach to care and support in England.

3.2.1.1 The Human Rights Act 1998

The Human Rights Act 1998⁽⁵¹⁾ brings most of the fundamental rights and freedoms contained in the European Convention on Human Rights directly into UK law. The Act protects 16 rights including: the right to life; the right not to be tortured or treated in an inhuman or degrading way; the right to liberty; the right to a fair trial; the right to respect for private and family life, home and correspondence; and the right to peaceful enjoyment of possessions. Cases based on the rights and freedoms in the Act can be argued in a UK court or tribunal. The Act also requires that all public authorities, such as hospitals, schools, local authorities and courts, act in accordance with the ECHR rights in everything they do. According to the Act, all other legislation should also be interpreted and applied in a way that is consistent with the rights included in the Act.

3.2.1.2 The Care Act 2014

The Care Act 2014⁽⁵²⁾ sets out the responsibilities of local authorities in relation to the provision of adult care and support in England. These include human rights-related responsibilities such as: the promotion of individual wellbeing; the provision of information and advice that is accessible to all according to a person's individual circumstances and needs; and the safeguarding of adults at risk of abuse or neglect. The Care Act 2014 makes explicit that any registered care providers who are providing nursing or personal care to adults in either a home or care setting arranged or funded by a public authority are bound by the Human Rights Act 1998.

3.2.1.3 Health and Social Care Act 2008

The Health and Social Care Act 2008⁽⁵³⁾ established the Care Quality Commission (CQC) to regulate health and social care. The Act makes provision for reviews and investigations under the Mental Health Act⁽⁵⁴⁾ and makes other arrangements for the regulation of the healthcare professions. It also mandates the regulation of professionals through an independent regulator. The protection of vulnerable people using residential care is also strengthened by the Act, which ensures that any independent-sector^{*****} care home that provides accommodation together with nursing or personal care on behalf of a local authority is subject to the Human Rights Act 1998.⁽⁵¹⁾ The Health and Social Care Act 2008 (Regulated Activities)

***** Independent Sector refers to non-statutory bodies in the UK charged with providing health and social care services

Regulations 2014 set out specific activities that are regulated against by the CQC and include regulations relating to human rights such as: person-centred care (Regulation 9); dignity and respect (Regulation 10); need for consent (Regulation 11); safeguarding service users from abuse and improper treatment (Regulation 13).

3.2.1.4 The Mental Capacity Act 2005

The Mental Capacity Act 2005⁽⁵⁵⁾ is an Act that applies to England and Wales. It was developed with the aim of clarifying legal uncertainties and to update and reform the law in relation to decision-making on behalf of adults who have been assessed as not having the mental capacity to do so themselves. The Act defines “persons who lack capacity” and sets out a two-stage test for assessing capacity. According to the Act, a person lacks capacity to make a decision if:

- they cannot understand the information relating to the decision
- they cannot retain that information
- they are unable to use or weigh up the information in order to make a decision.

The Act also sets out a checklist on how to establish a person’s best interests when they lack capacity and a decision is being made on their behalf. This includes:

- encouraging the participation of the person using the service as much as possible in the process of establishing their best interests
- considering all the circumstances relevant to establishing a person’s best interests
- finding out a person’s past and present wishes and feelings and his or her beliefs or values
- avoiding discrimination against a person based on age, appearance, condition or behaviour
- assessing if the person might regain capacity and if this is the case, deciding if the decision could be postponed until they do.

Mental capacity advocates who can represent and support people who lack capacity in relation to certain decisions, for example serious treatment or where restrictions might be placed on their freedom and rights in their best interests, are also provided for in the Act. The Act allows for advance decisions in relation to the refusal of treatment and also for the withdrawal of an advance decision. The Act asserts that the withdrawal of an advance decision does not need to be in writing.

The Act provides a legal framework for the fair treatment of people who lack capacity. It also provides for the use of proportionate interventions. The ECHR articles with which the Act is compatible include: the right to life, prohibition of torture, the right to a fair trial, the right to respect for private and family life, and prohibition of discrimination.^(55,56)

3.2.2 Human rights organisations

3.2.2.1 Equality and Human Rights Commission

The Equality and Human Rights Commission (the Commission) was established by the Equality Act 2006. It is Britain's national equality body and national human rights institution. It commenced operation in 2007 as an independent, statutory non-departmental body. Since its inception, the Commission has taken responsibility for protecting and promoting equality and human rights for all. The Commission is a regulatory body with responsibility for enforcing the Equality Act 2010. Some of the Commission's specific functions include:

- measuring the state of equality and human rights in Britain and reporting these findings to Parliament
- advising the British government on the effectiveness of equality and human rights legislation
- promoting awareness and understanding of rights, through education, training and guidance
- encouraging the harmonisation of domestic law, policy and practice with international human rights standards
- enforcing the law and investigating breaches, including assessing and enforcing compliance with the public sector equality duty.⁽⁵⁷⁾

The Commission publishes a strategic plan every three years and a yearly business plan which highlights the focus of work for the year in question.⁽⁵⁷⁾ The Strategic Plan 2016-2019 addresses topic areas including dignity in care and the use of restraint.⁽⁵⁸⁾ The Equality and Human Right Commission also works in partnership with other organisations including other regulators, inspectors and ombudsman organisations to bring about improvements in particular sectors.

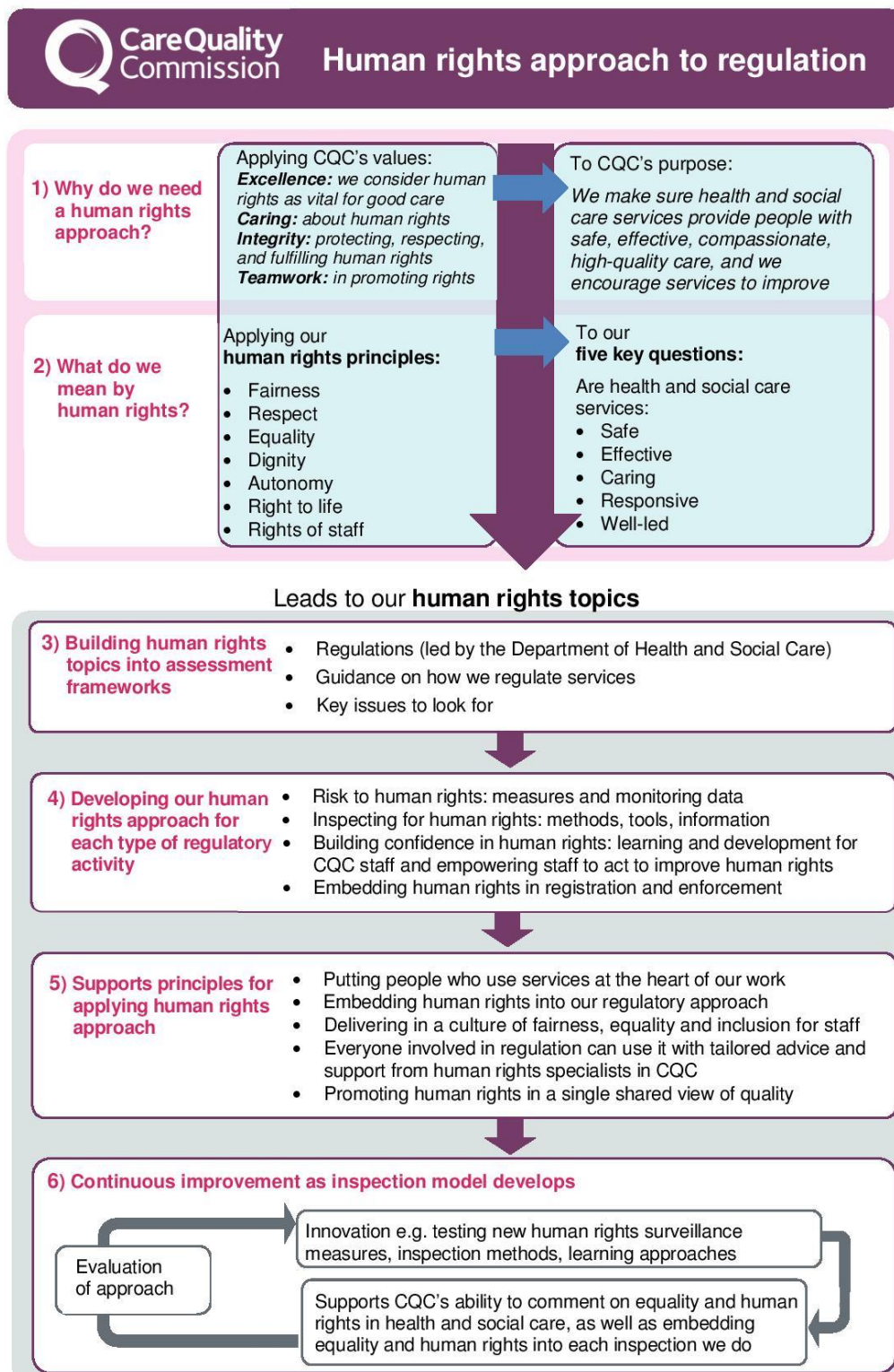
3.2.2.2 Care Quality Commission

The Care Quality Commission (CQC), established in 2009, is the independent regulator of health and adult social care in England. It regulates according to

standards produced by the Department of Health and Social Care with the aim of ensuring health and social care services provide people with safe, effective, compassionate, high-quality care. Where standards are not met, the Commission can take enforcement action. The Commission also works to encourage improvement in care quality in services. The Commission registers care providers; monitors, inspects and rates services; takes action to protect people who use services; and publishes its views on major health and social care quality issues.

In 2014, the CQC developed and adopted a human rights-based approach to their work. The need for this kind of approach was identified during the development of the CQC's 2013-2016 strategy, "Raising Standards, Putting People First".⁽⁵⁹⁾ It was seen as a way to ensure the fulfilment of the CQC's core purpose: to ensure good-quality care for everyone who accesses health and social care services. Underpinning this approach are the five FREDA principles and an additional two rights: the right to life and the rights of staff. These two rights have been added as they are seen as fundamental elements of a human rights-based approach in health and social care services. The infographic in Figure 2 illustrates the CQC's approach.⁽⁶⁰⁾

Figure 2: CQC's human rights approach to regulation



In order to roll out a human rights-based approach across areas within its remit, the CQC has:

- built human rights into its assessment frameworks
- applied the approach to its regulation
- carried out “pilots” when introducing new ways of regulating equality and human rights
- carried out an evaluation of the impact of the human rights-based approach in 2016 and a quality review of equality content in adult social care inspection reports in 2018
- added questions to provider and inspector surveys to get feedback on how well their inspections promote equality and ensure that human rights are upheld
- used equality objectives for quality improvement on specific topics.⁽⁶⁰⁾

Staff at the CQC are seen as an important element in ensuring that a human rights-based approach becomes embedded within the organisation. In order to promote the approach among staff, the CQC has:

- delivered a major learning and development programme for staff which covers mandatory introductory learning on equality and human rights principles for all staff; role-specific learning for inspection, registration and policy teams; and intensive learning for equality and human rights leads. This was delivered in partnership with the Equality and Human Rights Commission (the regulator for equality and human rights law in the UK) and the British Institute to Human Rights (a non-governmental sector organisation)
- developed a human rights network that allows staff to share experiences and learning internally and through regular meetings and an annual conference
- developed an “equality and human rights learning needs analysis” to meet the learning needs of inspectors and managers.

A provider survey is conducted annually by the CQC. Most recent results have shown that 70-75% of providers report that the work of the CQC in this area has an impact on the human rights of people using health and social care services.⁽⁶⁰⁾ There is on-going work in the area of assessing the impact of a human rights-based approach in services.

In 2018, the CQC reviewed the Human Rights Approach and identified 6 development priorities for the next four years. These are:

- considering how to embed equality and human rights in new types of work as they develop in the CQC, such as local system and area reviews, provider-level assessments and thematic work
- continuing to support staff to understand and act on equality and human rights in their role through learning and development, supportive methodology and the CQC equality and human rights network
- strengthening qualitative and quantitative information about equality and human rights in CQC Insight, especially in settings where people are at a higher risk of having their rights breached and where they may be less likely to be able to self-advocate
- working to maintain equality and human rights content in regulations and where possible, to improve it and develop how human rights issues are factored into enforcement decisions
- building on work with others to improve equality and human rights across health and social care, for example through aligning priorities and levers for change with other national bodies and engaging better with people who use services
- looking at how equality and human rights can be consistently considered in new ways of working in the CQC, including quality improvement, service design and digital development.⁽⁶⁰⁾

The breadth of the work undertaken by the CQC in the area of human rights highlights the importance of an organisation-wide commitment to establishing and maintaining this kind of approach. Taking an organisation-wide approach ensures a top-down and bottom-up adoption of a human rights-based culture that can have a positive impact on people who use health and social care services.

3.2.2.3 British Institute of Human Rights

The British Institute of Human Rights (BIHR) is an independent charity that provides people with up-to-date and accessible information on human rights. Its overarching remit is to ensure that the Universal Declaration of Human Rights is upheld in Britain. Within its remit, the organisation empowers people to:

- know what human rights are
- apply human rights in everyday practice to achieve positive change

- make sure that human rights are respected and progressed in laws and systems by those in power.

The work of the BIHR spans sectors and services such as justice, education and health and social care. They provide educational materials and talks to individuals and communities on human rights. Educational materials include guides for older people, carers and people with mental health problems, and fact sheets on human rights, the Human Rights Act and the ECHR. In addition to these educational materials, they also blog about legal developments, produce policy and legal briefings that highlight human rights issues and campaign to ensure people are accessing and protected by their rights under the Human Rights Act and the ECHR.

The BIHR also provides support to public sector and voluntary organisations working in the area of policy and practice, helping them to integrate human rights into their work. This support includes training and consultancy services. In 2014, the BIHR rolled out a project funded by the Department of Health and Social Care called Delivering Human Rights to the Frontline. The ultimate aim of the project was to improve outcomes for people using mental health and mental capacity services through enabling services to embed a human rights-based approach in their work. The BIHR worked with seven services and the output from the project was seven issue-specific toolkits discussed further in section 3.2.3.3.

In addition to this work, the BIHR worked on a second arm of the project which involved working with advocacy groups to ensure the dignified and respectful treatment of people with mental health and mental capacity issues while ensuring they have increased control and autonomy over treatment decisions.

The BIHR have also worked with regulators and public services to deliver programmes to staff on their duties in relation to human rights and equality and how to put these into practice. In addition to the above projects, the BIHR also has a website that provides useful resources and toolkits for people working in and accessing health and social care services. Resources include booklets and posters for people using services on their human rights, a series of practitioner guides in the areas of nursing, midwifery and end-of-life care funded by the Equality and Human Rights Commission, and short videos and animations.⁽⁶¹⁾

3.2.2.4 Mersey Care NHS Foundation Trust

Mersey Care NHS Foundation Trust (Mersey Care) in England provides specialist inpatient and community services that support mental health, learning disabilities, brain injuries, addictions and physical disabilities. It also offers high-security mental health facilities. Mersey Care ensures policies in place within the organisation

integrate equality and human rights approaches. All policy documents reaffirm the organisation's commitment to acting in accordance with the Human Right Act and the Equality Act and its commitment to the FREDA principles and a human rights-based approach in the delivery of care.

Each policy contains a Human Rights and Equality Analysis that outlines the impact the policy will have under eight specific human rights articles.

After adopting a human rights-based approach in one of their disability services, Mersey Care was also part of the British Institute of Human Rights project which worked with provider organisations to develop the practitioner guide, *Learning Disability and Human Rights: A practitioner's guide*.⁽⁶²⁾⁺⁺⁺⁺ Mersey Care has also developed a "No Force First" model of care which aims to reduce the number of incidents of restraint in its services and creates a supportive environment for staff to explore alternative options to restraint.

In its *Equality, diversity and human rights strategy 2018-2021*, Mersey Care states its commitment to enabling service users and carers to participate as equal partners in all aspects of the Trust to ensure the protection and promotion of the rights of vulnerable groups in its care.⁽⁶³⁾ A strong emphasis is also placed on the importance of taking care of staff through ensuring staff involvement in service development, respecting and celebrating diversity, and ensuring staff are supported in relation to inclusion and diversity issues.

3.2.3 Standards, guidelines and supporting tools and resources

3.2.3.1 Equally Outstanding: Equality and human rights-good practice resource⁽⁶⁴⁾

In 2018, the Care Quality Commission (CQC) produced a good practice resource on equality and human rights for health and social care services.⁽⁶⁴⁾ The resource was developed in partnership with a wide range of organisations involved in the delivery of health and social care services including: the NHS, Care England, Voluntary Organisations Disability Group and Skills for Care.

The publication focuses on the issue of promoting equality and human rights in times of financial constraint. It sets out the ethical, business, economic and legal case for services adopting a human rights-based approach. It provides case studies from health and social care services that have adopted this kind of approach in their work. It also includes a section on the importance of promoting and ensuring

⁺⁺⁺⁺ More details on this project can be found in section 3.2.3.3

workforce equality which can have a positive impact on the quality of services provided even during times of reduced resources.

Finally, the document sets out the importance of a whole-system approach to putting equality and human rights at the heart of service and quality improvement. This whole-system approach includes:

- commissioners
- regulators
- policymakers
- service providers
- people using services and their representative organisations.⁽⁶⁴⁾

3.2.3.2. National Institute for Health and Care Excellence (NICE) Guideline – Violence and aggression: short-term management in mental health, health and community settings⁽⁶⁵⁾

The National Collaborating Centre for Mental Health developed the NICE guideline in 2015. It sets out how to manage violence and aggression in mental health, health and community settings. The document emphasises the importance of staff training in the understanding and application of the Human Rights Act 1998, the Mental Capacity Act 2005 and the Mental Health Act 1983, particularly in relation to restrictive interventions.

Within the guideline, the key priorities for implementation are set out under the following headings:

- Anticipating and reducing the risk of violence and aggression
- Preventing violence and aggression
- Using restrictive interventions in inpatient psychiatric facilities
- Managing violence and aggression in emergency departments
- Managing violence and aggression in community and primary care settings
- Managing violence and aggression in children and young people

The guideline recommends principles for managing violence and aggression which are person-centred and human rights-based, including:

- improving service user experience
- involving service users in decision-making
- preventing violations of service users' rights.⁽⁶⁵⁾

The guideline gives advice on how services can work to reduce restrictive interventions which includes staff training in a person-centred approach; addressing environmental factors that can increase or decrease the need for restrictive interventions; involving and empowering the people using their services and their carers. The guideline makes clear that for every recommendation it makes, it expects there to be discussion with the person using the service about the benefits and risks regarding any intervention and that the discussion takes into account the person's preferences and values.

3.2.3.3 Shining a Light Series

The Shining a Light series of practitioner's toolkits is produced by the British Institute of Human Rights (BIHR). Initially, the BIHR collaborated with seven services and produced seven issue-specific toolkits that focus on different areas of practice in mental health, including:

- Dementia and Human Rights: A practitioner's guide (produced with Bristol Dementia Wellbeing Service)⁽⁶⁶⁾
- Learning Disability and Human Rights: A practitioner's guide (produced with Mersey Care NHS Foundation Trust)⁽⁶²⁾
- Mental Health Care for Children and Young People and Human Rights: A practitioner's guide (produced with The St Aubyn's Centre)⁽⁶⁷⁾
- Mental Health Early Intervention: A practitioner's guide (produced with Tees, Esk and Wear Valleys NHS Foundation Trust)⁽⁶⁸⁾
- Mental Health Accommodation Support and Human Rights: A practitioner's guide (produced with St Martin of Tours Housing Association)⁽⁶⁹⁾
- Rehabilitation and Human Rights: A practitioner's guide (produced with Avon and Wiltshire Mental Health Partnership NHS Trust)⁽⁷⁰⁾
- Social Care Intervention and Human Rights: A practitioner's guide (produced with Bristol City Council).⁽⁷¹⁾

Originally part of a pilot programme funded by the Department of Health and Social Care with a specific emphasis on mental health and mental capacity services, the

guides have continued to be produced with the most recent guide “Hospital Discharge and Human Rights” developed with St Martin of Tours hospital and published in 2018.⁽⁷²⁾

The guides are legally focused with all of the rights as set out in the Human Rights Act (HRA) listed in the guide. They are written in accessible language. Each guide includes information about the topic it will be discussing; key areas where potential human rights issues can arise in relation to the topic; specific rights that can be impacted; and a practitioner’s duties in relation to these rights in accordance with the HRA. The guides also provide useful examples of real-life situations where human rights issues can arise. Additionally, they provide practitioners with useful decision-making flow charts that highlight which Human Rights Act duty is triggered and what steps can be taken to ensure a positive outcome for the person using the service that does not impinge on their human rights. Flow charts are accompanied with an explanatory note for each stage of the decision-making process. At the back of each guide is further information on where practitioners can get more information on human rights in their work.

3.2.3.4 No Force First: A guide to reduce restrictive practice in mental health services⁽⁷³⁾

No Force First (NFF) is a programme used by Mersey Care. The principles underpinning the NFF philosophy are in line with a human rights-based approach to care. Mersey Care has declared itself an NFF organisation. After piloting the programme in three of its wards in 2013, it extended the programme to all other wards and developed a guide detailing the process.⁽⁷³⁾

The guide provides a step-by-step approach to what staff need to do to implement the approach, including details on ward implementation and clinical practice implementation. It also indicates the benefits service users can expect to experience and outlines how changes can be measured. Key interventions that form part of the NFF programme include:

- NFF engagement sessions
- NFF ward criteria and reviewing restrictive practice
- positive handovers
- healthy communities
- individualised meaningful day

- debriefing for people using services and staff.

The guide also provides useful tools that can be used as part of the implementation of a NFF approach including a one-page plan template. This is a plan developed collaboratively with a person using a service that includes relevant historical details, risk and protective factors. In addition, the guidance provides information on how to monitor and evaluate changes that might improve the experience of a person using a service and reduce conflict and the use of restraint.

Data gathered from the original 2013 pilots showed a 50% reduction in restraint in year one.⁽⁷³⁾ There was also a reduction of 25% in staff sickness on pilot wards. Staff morale and satisfaction and the experience of people using services all improved. An independent assessment indicated that implementing the NFF programme could lead to a reduction in spending due to reduced staff absences caused by assaults and injuries.⁽⁷³⁾

3.2.3.5 Older people and human rights: a reference guide for professionals working with older people

In 2009, Age UK in collaboration with the British Institute of Human Rights developed the guide, *Older people and human rights: a reference guide for professionals working with older people*.⁽⁷⁴⁾ The guide provides practical information for professionals working with older people on the national and international legal framework underpinning their work. It helps to contextualise human rights by linking the right to the relevant law in the UK.

It highlights some of the common issues affecting older people in the UK and the human rights relevant to those issues. Issues highlighted in the guide include:

- elder abuse and neglect
- lack of dignity or privacy
- inappropriate medication
- detention
- confidentiality and access to information
- discrimination and disadvantaged groups.

Case studies presenting some of the common issues that arise are also provided. Additionally, the document gives an overview of some of projects and initiatives

taking place in the UK at the time of publication involving older people and human rights.

3.2.4 Summary and lessons learned from England

Human rights are embedded in England's legislation through the Human Rights Act 1998, the Care Act 2014, the Health and Social Care Act 2008, and the Mental Capacity Act 2005. Now, through the efforts of the CQC, a human rights-based approach is being promoted at a regulatory level which has an impact on service provision, as was seen from the results of the CQC's most recent provider survey. Findings from the survey have indicated agreement that the CQC's work in this area has an impact on the human rights of people using health and social care services.

The learning from England shows that key to the implementation of a human rights-based approach in services is a concerted effort from the top-down and bottom-up to ensure the approach takes root. This is demonstrated through the Mersey Care NHS Foundation Trust, which adopted the approach at a management level and has embedded it in the day-to-day work of staff through policy development, service development, staff training and the development and roll-out of the No Force First model of care. The active involvement of a human rights-based organisation such as the British Institute of Human Rights in the development of useful resources and tools based on the legal duty of services and front-line staff has meant that legal obligations are made accessible and understandable for those providing day-to-day care to people using services. The Shining a Light series brought together expertise from services and from legal experts which indicates that a partnership approach is key in moving the human rights agenda forward through making it relevant and implementable and not something that is seen as abstract.

3.3 Scotland

Human rights are enshrined in Scotland's legislation and promoted within the culture of its health and social care services. This section presents the current status of human rights in Scotland and the on-going work being carried out in this area. It provides an overview of the educational tools and resources that have been developed to support services to implement a human rights-based approach in health and social care services.

3.3.1 Legislation

In Scotland, human rights are protected by the ECHR. The ECHR sets out the basic human rights and provides a framework within which the Scottish government and all other public bodies must act.⁽⁷⁵⁾ Although the ECHR has existed since 1950, the UK's Human Rights Act (1998)⁽⁵¹⁾ and the Scotland Act 1998⁽⁷⁶⁾ brought the rights

set out in the ECHR directly into the law of Scotland. Together, these Acts provide a framework within which Ministers, the Parliament and public authorities must operate in conducting their activities. The Acts work together and ensure that human rights are properly protected and upheld and are directly enforceable in Scotland's national courts. They provide an important means for protecting the most vulnerable people in society. These Acts, in addition to adult safeguarding legislation, the Adult Support and Protection (Scotland) Act 2007⁽⁷⁷⁾ and the recognition of the UN Convention on the Rights of Persons with Disabilities, ensure human rights are embedded in legislation.

3.3.1.1 The Scotland Act 1998

The Scotland Act 1998, which established the Scottish Parliament and the Scottish government, ensures that the Scottish Parliament can only pass laws that are compatible with human rights. This means that human rights must be respected and realised at all levels of governance in Scotland.^(75,78)

3.3.1.2 The Adult Support and Protection (Scotland) Act 2007

In 2007, Scotland passed specific adult safeguarding legislation, the Adult Support and Protection (Scotland) Act 2007. This came into operation in 2008.⁽⁷⁷⁾ The Act gives greater protection to adults at risk of harm and neglect.⁺⁺⁺⁺ The overarching principle of this Act is that any intervention in an individual's affairs should benefit the individual, should be the least restrictive option of those that are available and should meet the purpose of the intervention. The principles underlying the Act emphasise the importance of striking the balance between an individual's right to freedom of choice and the risk of harm. The Act places a duty on local councils^{§§§§§} to make inquiries and investigate cases where harm is known or suspected.

3.3.1.3 The UN Convention on the Rights of Persons with Disabilities

The UN Convention on the Rights of Persons with Disabilities (UNCRPD)^{*****} is not yet part of Scottish law, however it is used to understand and interpret the rights established in the UK Human Rights Act 1998, with respect to people with disabilities.

⁺⁺⁺⁺ An adult at risk is defined as a person who is aged 16 years and older and who: is unable to safeguard their own wellbeing, property, rights or other interests; and are at risk of harm; and because they are affected by disability, mental disorder, illness or physical or mental infirmity, are more vulnerable to being harmed than adults who are not so affected.

^{§§§§§} There are 32 local councils in Scotland. These provide public services, including education, social care, waste management, libraries and planning. They operate independently of central government and are accountable to their electorates for the services they provide.

^{*****} The UNCRPD is described previously in section 2.3.7

3.3.2 Human rights organisations

3.3.2.1 The Health and Social Care Alliance Scotland

The Health and Social Care Alliance Scotland is an organisation that works to embed human rights in health and social care policy and practice. The Alliance co-convened the Health and Social Care Action Group which was established under Scotland's National Action Plan for Human Rights (SNAP). The Alliance produces publications on human rights, has given evidence on human rights at the Scottish Parliament, and is a partner of the Scottish Human Rights Committee in an initiative on human rights budgeting.

3.3.2.2 The Scottish Human Rights Commission

The Scottish Human Rights Commission (SHRC) is an independent public body that promotes and protects human rights for everyone in Scotland. It was established in 2008 and is accredited as an "A" status National Human Rights Institution⁺⁺⁺⁺⁺ within the United Nations human rights system. The SHRC delivers extensive training and raises awareness on human rights among communities and organisations across Scotland. The SHRC has produced information about rights and has ensured these are available in an accessible format including animations, easy-to-read, British Sign Language BSL, infographic and plain English. For example, they have developed a series of short films illustrating rights in practice in health and social care.

3.3.2.3 Equality and Human Rights Commission

The Equality and Human Rights Commission (EHRC), an independent body, has a statutory remit to promote and monitor human rights across the UK. The Scottish division of the EHRC aims to eliminate discrimination, reduce inequality, protect and promote human rights, build good relations between people and ensure that everyone has a fair chance to participate in society. Its remit is to protect, enforce and promote equality across nine grounds: age, disability, gender, race, religion and belief, pregnancy and maternity, marriage and civil partnership, sexual orientation and gender reassignment.⁽⁷⁹⁾

⁺⁺⁺⁺⁺ To achieve an "A" status National Human Rights Institution, an organisation must be fully compliant with the Paris Principles which is assessed by six main criteria: Mandate and Competence, Autonomy from Government, Independence, Pluralism, Adequate Resources and Adequate Powers of Investigation. "A" status enables an organisation to be a voting member of the International Coordinating Committee of National Human Rights Institutions. "A" status organisations can also participate in sessions of the Human Rights Council, take the floor under any agenda item and can submit documentation.

3.3.3 Standards, guidelines and supporting tools and resources

3.3.3.1 Scotland's National Action Plan for Human Rights (2013-2017)⁽⁸⁰⁾

Scotland's National Action Plan (SNAP) on Human Rights 2013-2017 was the first of its kind in Scotland.⁽⁸⁰⁾ Based on evidence and extensive participation, SNAP was developed by a Drafting Group from across public and voluntary sectors including Amnesty International UK, Care Inspectorate, Convention of Scottish Local Authorities, Equality and Human Rights Commission, Health and Social Care Alliance, NHS Health Scotland, Scotland's Commissioner for Children and Young People, Scottish Council for Voluntary Organisations, Scottish Councils Equality Network, Scottish government, Scottish Human Rights Commission and the Scottish Trades Union Congress. SNAP aimed to work towards providing an opportunity for all parts of the health and social care landscape to use a human rights-based approach, and ultimately to achieve the vision of a Scotland where everyone can live with human dignity. It aspired to influence culture and leadership, and impact on the day-to-day delivery of services. SNAP advocated for a human rights-based approach based on participation, accountability, non-discrimination, empowerment and legality (PANEL). It provided a roadmap for the realisation of all internationally recognised human rights across Scotland. SNAP coordinated a wide range of public bodies and voluntary organisations to work together with those whose rights were at stake to agree what needed to be done, within a human rights framework. It pursued three outcomes supported by nine priorities. The three outcomes were:

- Better Culture – people understand and can affirm human rights and organisations are enabled and accountable to put human rights into practice.
- Better Lives – Scotland effectively tackles injustice and exclusion, improving lives.
- Better World – Scotland gives effect to its international obligations at home and internationally.

SNAP's activities over the period 2013-2017⁽⁸¹⁾ included supporting the Scottish government's development of a new social security system using a human rights-based approach; engaging with the review of the Health and Social Care Standards⁽⁸²⁾ through training, discussions and practical recommendations; and engaging with a review of NHS Complaints procedures.

With its four-year cycle complete, SNAP identified four areas to be strengthened in its next cycle. These include:

- Increasing participation by reaching out to others to build their understanding of what a human rights-based approach means in practice. This includes

involving people using services and their lived experience in shaping and guiding SNAP's strategy, management and actions.

- Making strategic choices by prioritising issues based on a broader evidence base. This involves aligning future activity with the recommendations from the United Nations Universal Periodic Review 2017 and recommendations for Scotland from international human rights treaty bodies.
- Demonstrating change through an agreed set of medium and long-term outcomes.

SNAP is currently being reviewed by a Development Working Group of representatives from civil society and the public sector. The second edition of SNAP will run until 2030 and there are plans in place to have a draft action plan ready for wider consultation by summer 2019. The report of an independent evaluation of SNAP will be published at the same time.

3.3.3.2 Mental Health Strategy (2017-2027)

Human rights were a key theme of the Scottish government's Mental Health Strategy 2012-2015, with Commitment 5 of the strategy stating: 'we will work with the Scottish Human Rights Commission and the Mental Welfare Commission for Scotland to develop and increase the focus on rights as a key component of mental health care in Scotland'. In 2017, the Scottish government published its Mental Health Strategy 2017-2027, which stated: 'Our vision for the Mental Health Strategy is of a Scotland where people can get the right help at the right time, expect recovery, and fully enjoy their rights, free from discrimination and stigma.'

3.3.3.3 Health and Social Care (HSC) Standards 2018

In April 2018, the Scottish government introduced the Health and Social Care (HSC) Standards.⁽⁸²⁾ The HSC Standards were introduced under section 50 of the Public Services Reform (Scotland) Act 2010⁽⁸³⁾ and section 10H of the National Health Services Scotland Act 1978.⁽⁸⁴⁾ The HSC Standards set out what the public should expect when using healthcare, social care or social work services in Scotland. They reflect a human rights-based approach to care and emphasise the importance of human relationships, kindness and compassion rather than focusing on physical inputs such as records, procedures, and health and safety. The HSC Standards moved away from policing services to comply with minimum standards to a more collaborative approach, helping each service to improve as much as possible. The HSC Standards provide one set of overarching standards, as shown in Figure 3, which are applicable to NHS services in Scotland, as well as services registered with the Care Inspectorate. The HSC Standards will help inform how the Care Inspectorate and Healthcare Improvement Scotland regulate and inspect health and social care services, as well as supporting improvement. Non-regulated services are

also expected to use the HSC Standards as a guideline to help achieve high-quality care.

Figure 3: Principles underpinning the HSC Standards

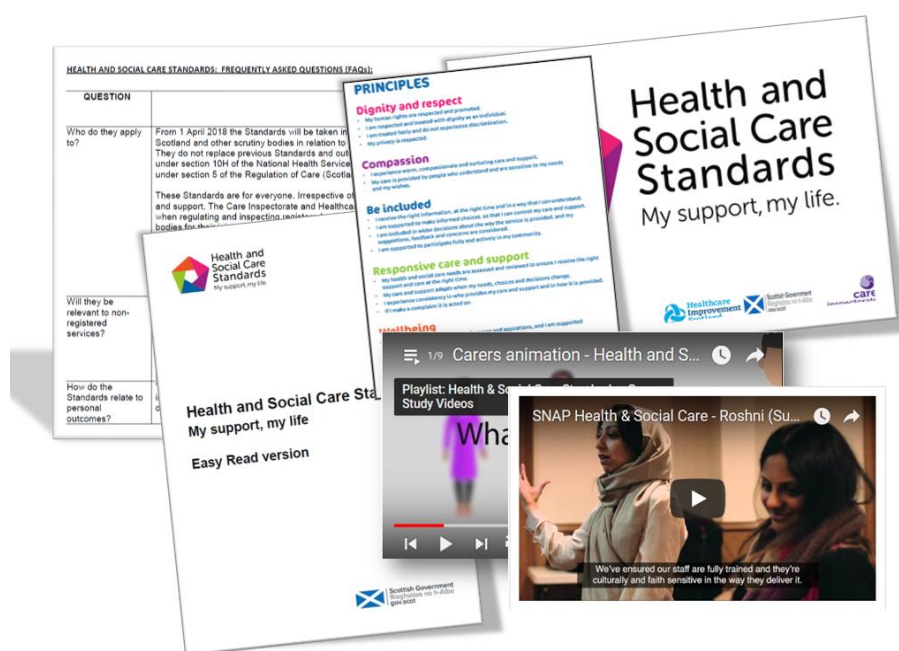


Supporting material has been developed to help inform and implement the HSC Standards, as shown in Figure 4.⁽⁸⁵⁾ These documents are published on the HSC Standards website.⁽⁸⁶⁾ Support material includes:

- videos of real stories, animations on the standards and case studies demonstrating a rights-based approach
- an easy-to-read version of the standards

- a PowerPoint slide deck used for information sessions including an audio version of the presentation
- an information leaflet on the standards
- a frequently asked questions (FAQ) section.

Figure 4: Support material developed to assist in implementing the HSC Standards



3.3.3.4 Care about Rights

Care about Rights is a project run by the Scottish Human Rights Commission (SHRC) to help realise the human rights of older people using care and support services. It is a set of training materials and resources designed for older people, carers, care workers, managers, Care Commission Officers, policymakers and commissioners of care. Care about Rights explains the benefits of applying human rights principles to everyday situations. The training is designed to increase awareness and knowledge of human rights issues, and give practical advice about how to apply human rights principles in the delivery of care. The SHRC have also developed an Equality and Human Rights Impact Assessment tool that is available for public authorities.⁽⁸⁷⁾

3.3.3.5 Rights in Mind

Rights in Mind is a booklet produced by the SHRC and supported by the Mental Welfare Commission.⁽⁸⁸⁾ It was designed to help staff in mental health services ensure that people using services have their human rights respected at key points in their treatment. The booklet features an illustrated pathway of a patient's journey through inpatient care, and provides a list of human and legal rights at each key

stage in their care and treatment. It is accompanied by good practice guidance and short films.

3.3.3.6 Being Human: A human rights based approach to health and social care in Scotland

Being Human: A human rights based approach to health and social care in Scotland⁽⁸⁹⁾ was developed by the Health and Social Care Alliance in Scotland. It contributes to the continuing conversation on human rights in Scotland, and particularly how human rights apply to health and social care and people who are disabled and living with long-term conditions. The document provides an overview of the recent history of human rights in the UK and Scotland; human rights legislation and policy in place in Scotland; and a description of what a human rights-based approach is as set out in the PANEL principles. It provides case studies of four initiatives in place within Scotland that promote a human rights-based approach in services for people who are disabled and are living with long-term conditions.

3.3.4 Summary and lessons learned from Scotland

Similar to England, human rights are embedded in Scotland's legislation through the Human Rights Act 1998, the Scotland Act 1998 and the Adult Support and Protection (Scotland) Act 2007. The Scottish government's newly revised overarching Health and Social Care Standards (2018) describe how services can take a human rights-based approach to care by emphasising the importance of relationships, kindness and compassion rather than focusing on physical inputs such as records, procedures, and health and safety. These standards inform how the regulatory organisations inspect health and social care services, and support improvement. Healthcare Improvement Scotland is currently developing a quality of care framework which will test if the standards are working and will allow services to demonstrate how they are being implemented.

The learning from Scotland shows that considerable progress has been made in the past ten years due to the collaborative work of human rights organisations and health and social care services. Progress can also be attributed to the publication of the National Action Plan on human rights and the support from the Scottish government in integrating human rights within its policy and health and social care standards. This is reflected in national strategies and standards for health and social care services in Scotland. Through the development of national standards, training material, booklets and manuals, services have been supported to increase their knowledge and understanding of human rights. However, it is important to note that while organisations such as the SHRC have recognised pockets of progress, they also recognise the need to sustain this change and further embed human rights systematically in the way Scotland's public services are delivered. This will require

investment in building the capacity of organisations, particularly when it comes to expanding their understanding of their broader international human rights obligations.⁽⁹⁰⁾

3.4 The Netherlands

In the Netherlands, there are well developed structures in place to protect the human rights of people who use services. This section provides an overview of some of the legislation, institutions, educational tools and resources that have been developed in the Netherlands to support services to implement a human rights-based approach in health and social care services.

3.4.1 Legislation

The Netherlands has been described in a 2016 European Commission report on patients' rights as a country that 'belongs to the patients' rights pioneers'.⁽⁹¹⁾ The Netherlands is one of only three countries in the European Union that formally recognise the right of the person using services to participate in clinical decision-making and on their choice of treatment options.⁽⁹¹⁾ Following the reform of the Dutch healthcare system in 2006, patients have also had a greater opportunity to influence the quality of services they receive and have greater rights to receive information they need to make an informed choice on their healthcare provider.

In the Netherlands, human rights are protected by a range of legislation including the Dutch Constitution⁽⁹²⁾ and international human rights agreements,⁽⁹³⁾ as described below. The Ministry of the Interior and Kingdom Relations is responsible for determining whether draft legislation is compatible with the Dutch Constitution and international human rights agreements. The Ministry of Security and Justice, which bears special responsibility for the quality of legislation in the Netherlands, examines all bills to determine (among other things) whether human rights aspects receive sufficient attention in their accompanying explanatory memorandum.⁽⁹⁴⁾

3.4.1.1 The Dutch Constitution

Many of the human rights set out in Chapter 1 of the Dutch Constitution are relevant to health and social care settings.⁽⁹²⁾ Article 22 of the Constitution sets out the obligation of the government to take steps in promoting the health of the population, living conditions, cultural self-realisation and recreational activities. Other articles of the Constitution play a role in determining how this is done. These include article 1 (equal treatment), article 10 (respect for privacy), article 11 (inviolability of a person's body), article 13 (respect for privacy of correspondence), and article 15 (respect for liberty). Several of the fundamental rights enshrined in the Constitution are further elaborated in specific acts of parliament. For instance, the Equal

Treatment Act implements the principle of equality, partly in relation to other fundamental rights and the Personal Data Protection Act implements the right to respect for privacy.

3.4.1.2 International Human Rights Agreements

The Netherlands is a party to international human rights agreements, many of which are derived from the Universal Declaration of Human Rights.

The Netherlands has signed and ratified the following human rights agreements:

- the Convention on the Rights of Persons with Disabilities
- the European Convention on Human Rights
- the International Covenant on Civil and Political Rights
- the International Covenant on Economic, Social and Cultural Rights
- the International Convention on the Elimination of All Forms of Racial Discrimination
- the Convention on the Elimination of All Forms of Discrimination against Women
- the Optional Protocol to the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment
- the Convention on the Rights of the Child
- the International Convention for the Protection of All Persons from Enforced Disappearance
- the European Social Charter.

There are several conventions that the Netherlands has signed but not yet ratified. These include the UN convention on the rights of migrant workers; the Council of Europe conventions on biomedicine and on violence against women; and one of the Supplementary Protocols to the European Convention on Human Rights.⁽⁹⁴⁾

3.4.2 Human rights organisations

3.4.2.1 The Netherlands Institute for Human Rights

The Netherlands Institute for Human Rights (the Institute) was founded in 2012. It is the 'A' status national human rights institute and equality body of the Netherlands.⁽⁹⁵⁾ The Institute was established by the Netherlands Institute for Human Rights Act, which sets out the mandate and tasks of the Institute.⁽⁹⁶⁾ Its aim is to raise awareness of human rights in the Netherlands in order to guarantee that they are respected and complied with. It is the independent supervisor of human rights in the Netherlands and it protects, advances, monitors and explains human rights. The Institute coordinates education on human rights and research into human rights. The Institute also investigates human rights issues, provides solicited and unsolicited advice concerning draft legislation and policies, and cooperates with civil society and international human rights bodies.⁽⁹⁷⁾

In its Strategic Plan (2016-2019), the Institute identifies a number of themes to proactively work towards. One of these themes involves working to embed human rights education into general education programmes, for example primary, secondary and further vocational education. In the plan, the Institute also recognises the need for making human rights more accessible to professionals and ensuring that professionals acknowledge the importance of human rights in their day-to-day work. Initially, the Institute focused on increasing the expertise of teachers so that future teachers would know more about human rights. However, it has also recognised the need to engage with institutions and professional bodies that provide care and support. The Institute has consulted with a range of third-level institutions to date, including those providing training in disciplines such as psychology and social work.

Concerns were raised in 2015 regarding the introduction of a comprehensive decentralisation of social services. This decentralisation project means citizens have to take more responsibility to organise their own care through their social network. This has resulted in adverse effects in relation to the provision of care among the elderly, children in care, and people with intellectual disabilities.⁽⁹⁸⁾ Concerns related to access to care, the way in which local governments deal with sensitive and private information, and on social exclusion of these groups. In response, the Institute's Strategic Plan aims to support local governments to apply the human rights framework within their policy development process. Ultimately, this programme aims to increase politicians' and policymakers' knowledge of human rights and the application of human rights in terms of both policy development and in delivering services.⁽⁹⁹⁾

Since the UN Convention on the Rights of Persons with Disabilities (CRPD) was ratified in the Netherlands in 2016, the Institute has assumed the role of supervisory body for the CRPD. In order to assess the implementation of the CRPD, the Institute has developed quantitative indicators to compare implementation over time.*****

These indicators measure aspects of accessibility, education, employment, independent living and participation in society. The Institute has also established a focus group to help monitor the implementation of the CRPD. The findings from the first measurement of the CRPD in 2016 showed that people with disabilities are at a disadvantage in participating in independent living, education and work.⁽¹⁰⁰⁾ In the Institute's 2018 submission to the Committee on the Rights of Persons with Disabilities, health services for persons with psychosocial conditions were described as often being unavailable in a timely manner. As a result of the existing waiting lists, people were not receiving proper care.⁽¹⁰¹⁾

One of the core values of the CRPD is the autonomy of the person. Article 12 stipulates that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life. If people are unable to make their own decisions, they must be supported with making decisions. The Institute commissioned VU University Amsterdam to examine the system of representation in the Netherlands. The research concluded that a number of laws in place require adjustment in particular with regard to the presumption of incapacity. The Institute is now examining what changes must be made to the law and are in contact with the relevant ministries.⁽¹⁰⁰⁾

3.4.2.2 Johannes Wier Foundation

The Johannes Wier Foundation (the Foundation) was established in 1986. It is an independent, charity-run organisation funded through donations. The aim of the Foundation is to promote compliance with human rights in healthcare and to ensure this remains on the central government's agenda in the Netherlands. The Foundation is involved in the implementation of a number of projects in the field of ethics, human rights and healthcare. It promotes knowledge and expertise in the field of human rights and healthcare by providing independent information and information about human rights and healthcare to doctors, nurses and other medical professionals.⁽¹⁰²⁾

Educational material developed by the Foundation includes brochures, guides and guidelines. These educational resources address topics such as providing care for asylum seekers and undocumented migrants, patients in the prison system and

***** A human rights indicator acts as a gauge that provides information relevant to a specific human rights standard. A human rights indicator does not 'measure' the compliance with an article of a convention, but it does provide an insight into a particular aspect related to an article.

patients on hunger strike. In addition, it produces research reports and position papers. Where necessary, the foundation collects testimonials from medical professionals about abuses in healthcare and raises them with policymakers or the media. The Foundation publishes a newsletter four times a year, with current news and its agenda and it distributes its newsletter electronically to interested parties.⁽¹⁰³⁾

The Foundation works closely with Dutch human rights organisations which include the Royal Dutch Medical Association, Amnesty International, the Netherlands Institute for Human Rights and the Institute for Human Rights and Medical Examination.⁽¹⁰²⁾

3.4.2.3 Patient Rights Organisations

Organisations such as the Patient Federation and Zorgbelang Nederland publish on their websites accessible summaries on patients' rights in the Dutch context.⁽⁹¹⁾ The summaries include easy-to-understand information using short, practical and relevant information and case-studies on a number of patients' rights areas such as:

- information rights
- informed consent
- right to free choice of provider
- right to confidentiality
- right to privacy
- right to access the medical file
- right to complain
- right to second opinion
- duties of patients.

In addition to the short information provided on the websites, the Patient Federation produces downloadable brochures with more extensive information.

3.4.3 Standards, guidelines and supporting tools and resources

3.4.3.1 The Netherland's National Action Plan on Human Rights

The Netherlands adopted a National Action Plan on Human Rights in 2013.⁽⁹⁴⁾ The National Action Plan sets out ways in which the government can methodically fulfil its responsibility to protect and promote human rights in the Netherlands. It sets out

the specific objectives and priorities of the government and the role of other bodies and individuals in ensuring respect for human rights in the Netherlands.

The Netherlands Institute for Human Rights has, however, identified a number of criticisms of the National Action Plan.⁽¹⁰⁴⁾ While the plan provides an overview of policies the government already has in place, the number of new plans and actions are limited. It is unclear who is responsible for the implementation of the National Action Plan and the government does not monitor its implementation. The Netherlands Institute for Human Rights Institute believes there should be more ambition to create an infrastructure to improve the implementation of human rights obligations across all ministries. A more comprehensive and all-encompassing action plan could encourage the various government departments to fully integrate human rights in their work.

3.4.3.2 The Johannes Wier Foundation Educational Resources

The Johannes Wier Foundation (the Foundation) has developed a number of educational resources, including guidelines and brochures to support healthcare professionals to understand how they can protect and promote human rights in their practice. One of these resources is *The right to health: a 'toolkit' for healthcare professionals*.⁽¹⁰⁵⁾ This document highlights the importance of practical interpretation of the right to health for professionals in their daily practice. The toolkit acknowledges that many professionals already work in ways that promote and protect the right to health, and that putting the right to health into practice does not mean a new way of working. The toolkit provides practical tips to professionals to ensure their daily practice is in line with human rights legislation.

The Foundation delivers presentations and training on request from healthcare organisations. They also organise various debates in collaboration with professional organisations and academies. Since 2011, the Foundation has held a symposium each year on Human Rights Day.

The Foundation develops accredited e-courses for information and education in the field of healthcare and human rights. E-courses developed to date address current issues such as healthcare for undocumented migrants and ethical dilemmas in mental health care for asylum seekers.⁽¹⁰³⁾

3.4.3.3 The Netherlands Institute for Human Rights

In 2016, the Netherlands Institute for Human Rights published the report, *Putting the Client First*.⁽¹⁰⁶⁾ The focus of this report was on human rights in nursing home care and it involved an analysis of practices in six Dutch nursing homes. The findings showed that human rights were well respected in most regards, but that a number

of issues required attention. One of the findings of the report was that nursing home residents often have too little to do and nursing homes must provide activities for those who can and still wish to participate in them. This report provides a basis for practical improvements. Since its publication, the report has been used to inform the development of the National Health Care Institute's Nursing Home Care Quality Framework (2017).^(100,107) It has also led to the launch of the government's 'Dignity and Pride' action plan to ensure that people using nursing homes are provided with care while retaining their dignity.⁽¹⁰⁶⁾

3.4.3.4 Human Rights at the Heart of Social Work (Education): An Appeal for a Human Rights-Based Approach

In 2016, a Working Group published a Dutch and English language manifesto entitled, *Human Rights at the Heart of Social Work (Education)*. The aim of this manifesto was an appeal for a human rights-based approach in social work education. The manifesto contains five pillars to progress the overall goal:

- Recognise human rights as both a socio-political framework and a framework for social practice.
- Embed human rights in the social work curricula in an integrated and explicit way.
- Learn how to use human rights as a framework for self-critical social work.
- Work towards the professional development of lectures in the field of social work and human rights.
- Initiate scientific research to boost the incorporation of human rights into the curricula of social work.

The manifesto has been signed by over a hundred lecturers, professors, opinion leaders, and advocacy groups in the Netherlands. The Working Group has also drafted an Action Plan (under review at the time of writing this report) which contains pivotal steps needed to achieve the interim milestones and objectives as set out in the manifesto.⁽¹⁰⁸⁾

3.4.4 Summary and lessons learned from the Netherlands

Human rights are protected in the Netherlands by national legislation and international human rights agreements and provisions are made to ensure draft legislation is compatible with human rights. Central government in the Netherlands plays an active role in protecting human rights and continually monitors whether new policies or legislation are needed in order to protect human rights.⁽⁹⁴⁾

Additionally, all draft legislation is assessed to ensure it is compatible with the Dutch Constitution and international human rights agreements. In 2013, the Netherlands adopted a National Action Plan on Human Rights which sets out the specific objectives and priorities of the government and the role of other bodies and individuals in ensuring respect for human rights in the Netherlands.

The Netherlands has an 'A' status National Human Rights Institution (the Netherlands Institute for Human Rights) in place since 2012 which works to protect, advance, monitor and explain human rights in the Netherlands. The Institute has assumed the role of supervisory body for the CPRD since its ratification, which it monitors through human rights indicators. In relation to promoting knowledge and expertise in the field of human rights and health and social care, both the Institute and the Johannes Wier Foundation provide information about human rights for policymakers and practitioners working in area of care and support. The Johannes Wier Foundation has produced a range of educational resources, research and reports to date. The Foundation also regularly delivers training and symposia for healthcare professionals to raise their awareness of current human rights issues and to support them to deliver care that reflects a human rights-based approach.

As with other jurisdictions, findings from the Netherlands highlight the importance of embedding human rights in legislation. Using this legal incentive, human rights initiatives and resources can be developed at organisational and service delivery level.

3.5 Iceland

Human rights are enshrined in Iceland's legislation. Although there is no national action plan specifically on human rights in Iceland, the legal obligation to uphold a person's human rights is set out in various acts relevant to health and social care services. Iceland also has an inter-ministerial steering group on human rights, of which Iceland's Minister for Health is a member.

The Directorate of Health in Iceland is in charge of overall inspection, monitoring and regulation of healthcare services including hospitals, nursing homes, primary care centres, specialist services and services provided by other healthcare personnel such as physiotherapists and psychologists. The Directorate's remit also includes regulation and licensing of healthcare professionals; setting standards for healthcare quality and clinical guidelines; organising public health measures and sponsoring health promotion initiatives; collecting and processing data on health and healthcare services; and promoting research and handling complaints from healthcare users. While inspections are based on legislation such as the Medical Director of Health and Public Health Act 2007,⁽¹⁰⁹⁾ Health Service Act 2007⁽¹¹⁰⁾, Patients' Rights Act

1997,⁽¹¹¹⁾ and the UN Global Goals,⁽¹¹²⁾ human rights are not specifically addressed in inspections and reports.^{§§§§§§}

The following section will outline the relevant legislation that relates to human rights in health and social care in Iceland.

3.5.1 Legislation

3.5.1.1 Constitution of the Republic of Iceland No.33/1944⁽¹¹³⁾

The Constitution of Iceland represents the highest national legal authority. It has been revised seven times. Fundamental changes have been made to the Constitution based on the European Convention on Human Rights. Human rights are set out in Chapters 6 and 7 of the document. The chapters protect many human rights including freedom of religion, equality, prohibition of torture, right to privacy, home and private life, and right to a fair trial. Article 76 of Chapter 7 of the Constitution also guarantees health and social care assistance for all.⁽¹¹³⁾

3.5.1.2 European Convention on Human Rights No. 62/1994⁽¹¹⁴⁾

The European Convention on Human Rights (ECHR) was incorporated into Icelandic law by Act No. 62/1994.⁽¹¹⁴⁾ Following its incorporation, its provisions can be directly invoked in court as domestic legislation.

3.5.1.3 Patients' Rights Act No 74/1997⁽¹¹¹⁾

Based on the World Health Organisation (WHO) patient rights framework, the Patients' Rights Act came into force in Iceland in 1997. Article 1 of the Act sets out the specific purpose of the Act as follows:⁽¹¹¹⁾

'to ensure specific rights for patients in accordance with general human rights and human dignity and thus strengthen their legal status vis-à-vis the health service, and to support the confidential relationship which must exist between patients and healthcare practitioners. It is prohibited to discriminate against patients on grounds of gender, religion, beliefs, nationality, race, skin colour, financial status, family relationship or status in other respect.'

Although not explicitly linked to specific human rights articles of the ECHR, the Act encompasses them through its stipulation of various patient rights. The Act provides for the right of patients to access or not access information on their condition, treatment options and consequences of not accepting treatment. It also stipulates

^{§§§§§§} This was confirmed in personal correspondence with a senior medical officer in the Department of Supervision and Quality, Directorate of Health, on 5 April 2019.

that information must be understandable for a patient including the provision of an interpreter if the person is unable to understand Icelandic or uses sign language. The Act mandates consent be sought from a patient and upholds a patient's right to refuse treatment or consent.

Section 5 of the Act focuses on treatment and specifically stipulates respect for the human dignity of the patient as well as a patient's right to support from family, relatives and friends during their treatment or stay in a health facility. The Act also provides for a patient's right to make a complaint and mandates that a complaint be replied to at the earliest opportunity.⁽¹¹¹⁾

3.5.1.4 Act on the Affairs of Disabled People No. 59/1992⁽¹¹⁵⁾

The Act on the Affairs of Disabled People ensures that all people with disabilities (which includes intellectual disability, psychiatric illness, physical disability, blindness and deafness, as well as disabilities resulting from chronic illness and accidents) have access to a standard of living equal and comparable to the general population. Implementation of the Act is guided by the UN Convention on the Rights of Persons with Disabilities which was signed by Iceland in 2007 and ratified in 2016. The Act sets out the entitlement of people with disabilities to special supports and services as required. The Act also provides for the development of service standards, quality standards and the monitoring of services.⁽¹¹⁵⁾

3.5.1.5 Municipalities' Social Services Act 40/1991⁽¹¹⁶⁾

The Municipalities' Social Services Act requires local government to guarantee financial and social security and to work for the welfare of the population.⁽¹¹⁶⁾ The term 'social services' in the Act refers to, among others, services for the elderly and services for people with a disability. Article 42 of the Act specifically provides for the equal standard of living and opportunities for people with a disability as are enjoyed by other members of society. The Act stipulates the rights of a person with a disability to access general services and assistance as appropriate and possible, and notes matters not relating to the Social Services Act are subject to the Act on the Affairs of Disabled People.

3.5.2 Human rights organisations

3.5.2.1 Icelandic Centre for Human Rights

The Icelandic Centre for Human Rights is an independent organisation that aims to advance human rights through research, education and promotion of human rights issues in Iceland. The Centre monitors the status and implementation of human

rights in Iceland and also provides legal advice to immigrants. There are no specific projects undertaken by the centre that relate to human rights in health and social care settings.

3.5.3 Standards, guidelines and supporting tools and resources

3.5.3.1 A Reference Guide to Core Medical Training in Iceland

A Reference Guide to Core Medical Training in Iceland was published in 2016.⁽¹¹⁷⁾ The document is intended for all post-graduate trainees taking up core medical training in internal medicine but notes that it can be adapted for other speciality training in Iceland as needed. It was reviewed by the Directorate of Health, the Professor of Internal Medicine in the Medical School at the University of Iceland, the Chief Medical Officer at Landspítali University Hospital, Akureyri Hospital and the Icelandic Society of Internal Medicine and the Royal College of Physicians. The document sets out guidance in relation to all aspects of core training for medicine. In section four which relates to setting standards, the guide stipulates the requirement for trainers and trainees to have an understanding of human rights and equality legislation. It also stipulates that they embed human rights in their practice and behaviours to ensure that patients and carers have access to medical care that:

- is equitable
- respects human rights
- challenges unlawful discrimination
- promotes equality
- offers choices of service and treatments on an equitable basis
- treats patients and carers with dignity and respect.⁽¹¹⁷⁾

3.5.4 Summary and lessons learned from Iceland

Although there is no specific human rights national action plan in place in Iceland, the in-depth legislation relating to human rights provides a framework for the implementation of a human rights-based approach across health and social services. Human rights are protected within Iceland's Constitution and are further strengthened through legislation on patient's rights and the rights of people with disabilities. However, with no monitoring carried out on human rights specifically in the area of health and social care services and no specific guidance relating to this area, it is difficult to ascertain the level to which human rights are upheld in the day-to-day work of health and social care services in Iceland.

3.6 Summary of international review

This section presents the findings from an overview of human rights-based approaches across four jurisdictions: England, Scotland, the Netherlands and Iceland. Through comprehensive correspondence and a desktop review of relevant legislation, standards, guidance, and policies, this section highlights the following factors:

- The importance of embedding human rights in legislation and policy at central government and local levels. It is also important to ensure politicians and policymakers have a clear knowledge of human rights and the application of human rights in terms of both policy development and in delivering health and social care services.
- The important role that an 'A' status National Human Rights Institution plays in protecting, advancing, monitoring and explaining human rights.
- The important role that human rights-based organisations play in the development of useful resources, tools, training and engagement to support services in their awareness and understanding of their duty to protect and promote human rights in their day-to-day work. It is also important that these resources are developed through close collaboration with health and social care services.
- The importance of a concerted effort from the top-down and bottom-up to ensure the implementation of a human rights-based approach in health and social care services takes root.
- The importance of developing human rights indicators to monitor human rights. At a local level, this includes developing human rights and equality impact assessment tools for organisations to use to reflect on their service.
- The importance of developing a National Action Plan on Human Rights which sets out the specific objectives and priorities of the government and the role of other bodies and individuals in ensuring that human rights are upheld.

4. Evidence Synthesis Methodology

4.1 Overview of the evidence synthesis process

HIQA's Health Information and Standards Directorate undertakes detailed syntheses and reviews of existing literature and evidence to inform the development of national standards and guidance. These reviews describe the Irish and international context against which the work is being conducted, and ensure that the work is informed by quality evidence and reflects international best practice. This is detailed in HIQA's *Evidence Synthesis Process: Methods in the development of National Standards, Guidance and Recommendations for the Irish health and social care sector*.⁽³³⁾ The evidence synthesis process has two phases: Phase 1 involves a scoping review and Phase 2 consists of a systematic search and literature review.

4.2 Scoping review

The scoping review was a time-limited review and was a preliminary assessment of the potential size and scope of the existing literature and how long it would take to review relevant literature. For the purpose of this scoping review, subject matter experts in the area of safeguarding adults were consulted for advice. Through the scoping review, relevant databases and websites were identified. Three grey literature^{*****} repositories were identified: Lenus, HEN and Rian. The academic databases identified were: ASSIA, CINAHL, Pubmed, Social Sciences, SocINDEX, PsycInfo and Social Services Abstract. Official websites from the following organisations were also identified through the scoping review: the British Institute of Human Rights, Age UK, the Scottish Human Rights Commission and the Irish Human Rights and Equality Commission. The scoping review also informed the development of a tailored research question, search terms and search limiters. The returns were catalogued according to the type of article and the source of the article. The findings from the scoping review were integrated and used to inform Phase 2 of the evidence synthesis.

4.3 Objectives

The aim of the evidence synthesis was to assess and appraise published evidence to identify characteristics of human rights-based care and support practices for adults in health and social care settings.

Phase 2 of the evidence synthesis included the following objectives:

^{*****} Grey literature refers to information and research that is not commercially published. Examples of grey literature include newsletters, government reports and policy statements.

1. To conduct a formal systematic search of the following literature sources, as identified in Phase 1:
 - grey literature repositories
 - academic databases
 - identified websites.
2. To formally consult with stakeholders and subject matter experts through a scoping consultation to generate suggestions of evidence for inclusion in the evidence synthesis.
3. To screen all articles for inclusion in the evidence synthesis.
4. To conduct a quality appraisal of all included articles in the evidence synthesis.
5. To describe and critically evaluate the articles under the FREDA principles.

4.4 Search strategy methodology

4.4.1 Conducting a formal systematic search

Search terms identified in Phase 1 of the evidence synthesis were used to identify, retrieve and evaluate literature from academic databases and grey literature repositories.

Seven electronic academic databases were searched between August and September 2018: ASSIA, CINAHL, Pubmed, PsycINFO, SocINDEX, Social Services Abstract and Social Sciences. A key term search strategy was employed. Natural language and controlled vocabulary descriptors, for example MeSH (Medical Subject Headings) terms and CINAHL Headings, were used to describe each element within a search query. A combination of search terms was used; these related to the setting (for example, 'healthcare', 'social care', 'mental health'), and to the topic of interest (for example, 'rights-based care', 'human rights', 'human rights framework'). Terms such as 'practice', 'standard', 'guidance' and 'guideline' were included to classify the ways of providing a rights-based approach to care and support. The full list of terms used to search the academic databases is shown in Table 1.

Table 1: Search terms used to search academic databases

Concept 1	Concept 2	Concept 3
Health	Rights-based care	Guideline
Healthcare	Human rights	Practice
Social	Rights-based approach	Standard
Social care	Human rights approach to care	Best practice
Community care	Human rights framework	Guidance
Mental health		Principle
Homecare		

The identified websites and three grey literature repositories were searched. The search terms in Table 1 were also applied to the grey literature, however it was not possible to apply all combinations of search terms at one time. A more simplistic approach was taken with each source being searched iteratively using the terms outlined in Table 1.

4.4.2 Screening articles for inclusion

Evidence was deemed to be eligible for inclusion in the evidence synthesis if it described elements of a human rights-based approach to care and support being applied in a health or social care service for adults. Quantitative, qualitative, mixed methodologies, reviews and opinion pieces were considered in the evidence synthesis. The following exclusion criteria were applied at two stages of study selection (screening by title and abstract and during the assessment of the full text):

- documents focusing on services for children
- documents focusing on countries outside of Europe⁺⁺⁺⁺⁺
- books, book reviews and letters.

4.5 Scoping consultation and suggested resources

A scoping consultation was completed to inform the development of guidance to support a human rights-based approach in health and social care services for adults. The scoping took place during October 2018 and ran for a four-week period. The

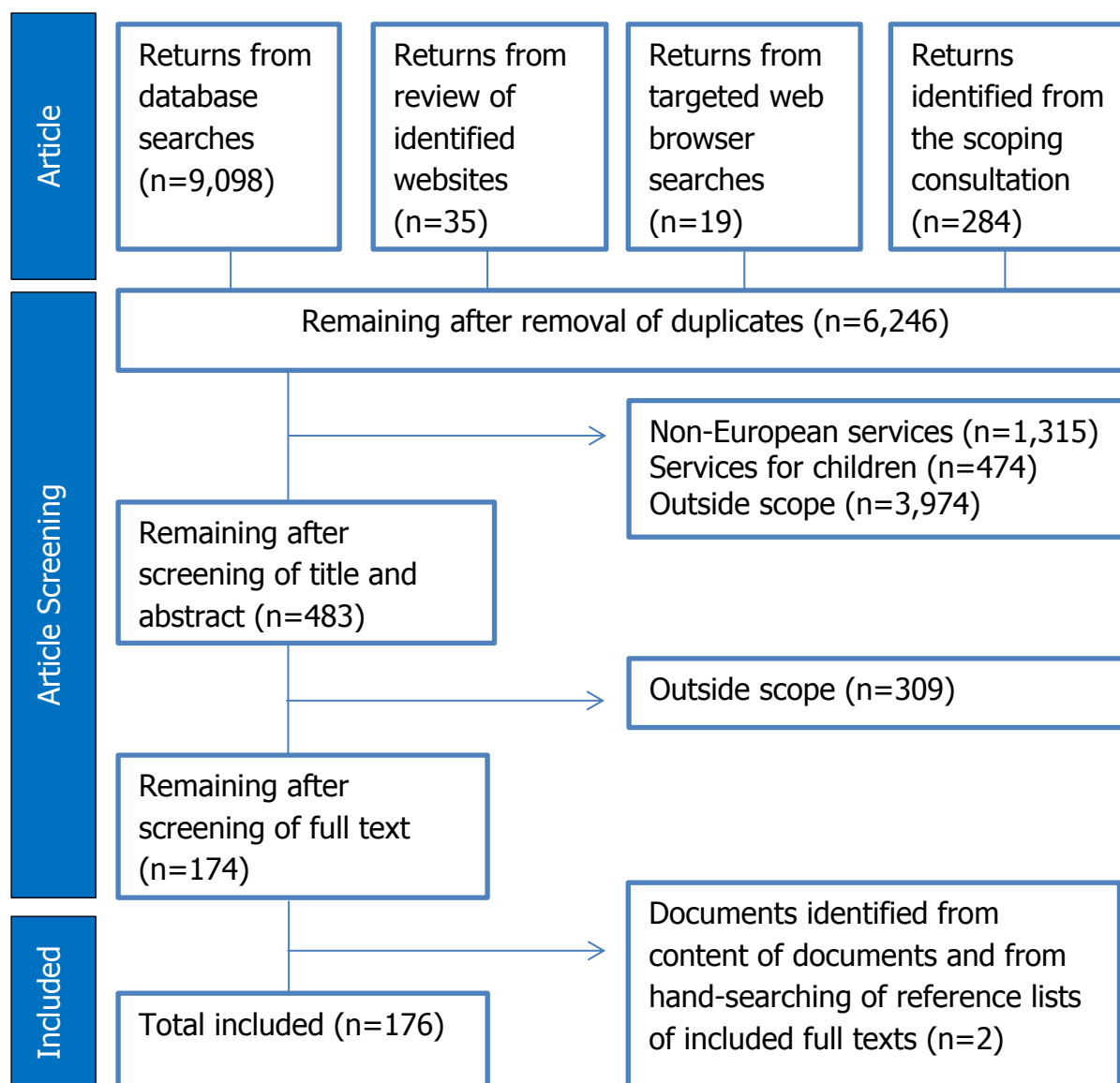
⁺⁺⁺⁺⁺ The purpose of the evidence synthesis is to determine how health and social care practitioners can incorporate human rights legislation into practice. This review focuses on States, including Ireland, who have signed up to the ECHR and are commonly bound, under international law, to secure to everyone within their jurisdiction the rights and freedoms set out in it.

purpose was to consult with people using services at the initial stages of the guidance development process. The consultation asked what areas the guidance should address and respondents were asked to provide examples of good practice. Respondents were also asked to provide key sources of evidence that would inform the development of the guidance. Following the removal of duplicate suggestions, 284 sources of evidence were suggested. These suggestions included legislation and laws, books and journal articles, and information on websites. All suggested sources of evidence were screened and reviewed for relevance.

4.6 Summary of search results

Figure 5 depicts a flow chart of the selection process, which was carried out between September and November 2018. Two reviewers independently screened titles and abstracts and extracted 9,436 as potentially relevant. Following the removal of duplicates, 6,246 potential documents were identified for inclusion. The remaining documents were read by two authors to determine eligibility for inclusion. Discrepancies about whether a paper met the inclusion criteria were discussed with a third author and a final decision was made based on consensus. Three hundred and nine (309) full texts assessed were deemed to be out of scope. Two additional documents were identified for inclusion in the evidence synthesis following a review of full texts and from hand-searching the reference lists of included full texts.

Figure 5: Prisma flow chart for evidence synthesis



4.6.1 Quality appraisal

The AACODS checklist^{(118)*****} was used to appraise the quality of the grey literature and assessed the literature using the following criteria: Authority, Accuracy, Coverage, Objectivity, Date and Significance. A total of 63 grey literature documents were assessed using the AACODS checklist. Overall, these articles made a significant contribution to the evidence synthesis. The articles came from reputable and credible authors or organisations and the findings were presented in a balanced and objective manner. There were, however, a number of grey literature articles

***** The AACODS checklist is designed to enable evaluation and critical appraisal of grey literature.

that did not include a bibliography, a methodology or evidence of peer review or editing by a reputable authority.

The Critical Appraisal Skills Programme (CASP)⁽¹¹⁹⁾ was used to assess the quality of 14 qualitative studies, one cross-sectional study and two systematic reviews. One literature review and one qualitative study were found to be of poor quality and did not contribute to the evidence synthesis. In addition, five of the 14 qualitative studies did not provide details of a rigorous analysis being applied. A further 94 peer-reviewed academic articles were also assessed using the AACODS checklist as they did not have a methodology consistent with a particular CASP checklist. In terms of significance, 21 articles were found to have limited or no significant input into the evidence synthesis.

5. Evidence synthesis findings

5.1 Structure of the literature review

As outlined in section 1.3, the FREDA principles of Fairness, Respect, Equality, Dignity and Autonomy, and synonyms for them, clearly emerged as themes in the literature and thus have been used to structure this section.^(38,39) Findings are discussed under each of the principles.

As noted in section 1.3, while it is useful to consider each of the FREDA principles separately, a human rights issue can relate to more than one principle. For example, informed consent relates not just to autonomy but also to respect and fairness. Ensuring that a person's right to autonomy is upheld in the area of informed consent requires a clear and fair process governing informed consent to be in place. It also requires that service providers show respect for a person's will and preferences. In the area of restrictive practices and restraint, upholding a person's dignity requires that their autonomy is not unnecessarily affected through excessive restraint. Fair and consistent procedures in the area of restraint and restrictive practices can ensure the principle of fairness is upheld. In relation to physical examinations of people using services, upholding a person's dignity requires healthcare practitioners to show respect to the person by draping them appropriately and asking them for permission to enquire about sensitive matters in their history or to conduct an uncomfortable examination. In the literature review, topics that relate to more than one principle are discussed in the context of each relevant principle.

5.2 Principle 1: Fairness

5.2.1 Introduction

Fairness has been defined as 'the principle that demands that due consideration is afforded to the person's opinion, giving them the opportunity to have that point of view expressed, listened to and weighed, alongside other factors relevant to the decision to be taken.'⁽¹²⁰⁾ Fairness is described in a report by the UK's Care Quality Commission⁽³²⁾ as 'people using services having access to clear and fair processes for having their views heard, for decision-making about care and treatment, and to raise and resolve concerns or complaints'. It is important to ensure that there is a degree of certainty to the processes in place in order to allow other people using services to determine how they would be treated in similar circumstances.⁽¹²⁰⁾

A human rights-based approach means putting the human being and their legally protected rights at the centre of policymaking and day-to-day practice.^(121,122,123)

Article 6 of the Universal Declaration of Human Rights (1949) states that everyone has the right to be recognised everywhere as a person before the law. People have

the right to exercise their legal capacity on an equal basis with others in all aspects of life.⁽¹⁰⁾ Article 6 of the European Convention on Human Rights states that everyone has the right to a fair trial. This has been described in the context of health and social care settings as going beyond the process of a legal trial and including decision-making processes, for example making a complaint, making a compensation claim, and commencing staff disciplinary proceedings or tribunals in health and social care settings.⁽¹²⁴⁾

This section sets out how health and social care providers can ensure fair and consistent processes are at the centre of their practice. The following areas in particular are discussed:

- the provision of accessible information
- obtaining consent for a treatment or intervention
- the processes applying a human rights-based approach to decision-making in a health or social care setting
- confidentiality of personal information
- risk assessment
- restrictive practices
- making a complaint.

5.2.2 Provision of accessible information

In 2013, the Alzheimer's Society of Ireland held a human rights workshop with stakeholders including older people, organisations representing older people, and service providers from a variety of organisations and sectors in Ireland. One of the key issues that emerged was the lack of access to appropriate and timely information.⁽¹²⁵⁾ People using services must be provided with comprehensive and accessible information that allows them to make independent choices.^(125,126,127) They should also have access to information about their human rights.⁽¹²⁸⁾ This cannot be addressed without considering the person's expressed preferences for the format and manner in which they receive information, and the need to provide information in ways that are meaningful and accessible to people with intellectual or physical disabilities.⁽¹²⁵⁾

A number of practices can enhance the accessibility of information in healthcare settings, including repetition and providing information tools such as leaflets and video resources.⁽¹²⁹⁾ Information should be clear and simple and should avoid medical terminology.⁽¹²⁷⁾ For the social care setting, a booklet has been developed

by the British Institute of Human Rights which emphasises the importance of making sure that people with intellectual disabilities are aware of their right to make decisions about personal relationships. The booklet provides accessible information to help people with intellectual disabilities to make decisions about personal relationships. It provides information on how they can access independent advocacy in situations where there are restrictions placed on their freedom to form and maintain personal relationships, marry or to have a family.⁽¹³⁰⁾

In relation to information being provided to an individual about their own health status, a UK paper recommends that every person has the right to receive information about their own condition, their treatment, and their healthcare providers.⁽¹³¹⁾ A progress review by the Office of the Ombudsman on advancements made since its publication of *A Good Death* report in 2014 discusses how information should be conveyed to a person using services.⁽¹³²⁾ The report states that people using services have a right to receive or not receive bad news and can decide how much information they feel they need. People using services also have a right to decide who should be present during a consultation with a health practitioner and have a right to ask that other members of the multi-disciplinary team be present when bad news is being communicated to them or during on-going consultations.^(129,132)

5.2.3 Obtaining consent for a treatment or intervention

Informed consent is a process which guarantees that freedom, privacy and safety are upheld for a person using services. Additionally, it maintains trust between healthcare practitioners and people using services. It is important for there to be a clear and fair process in place to ensure that a person's rights are upheld in this respect. The healthcare practitioner performing a procedure is responsible for obtaining the person's consent. Both the healthcare practitioner and the person using services must actively participate in the informative process in order to complete informed consent.

To arrive at informed consent, it is important that adequate information about all aspects of a procedure is provided to the person and that this information is sufficient and accurate. Adequate information includes explanations and details of the benefits and risks of the proposed and alternative treatments; it also includes the option and consequences of no treatment.^(127,131,133) Consideration must be given to the quality of the communication between the service provider and the person using services, both in terms of information content and how the information is provided. It is important that the information is provided in a way that does not increase anxiety or decrease confidence in the procedure. People using services should be encouraged to ask questions and their understanding should be

checked.⁽¹²⁷⁾ It must also be ensured that when a person starts treatments, the implications for different treatment choices available are thoroughly discussed with them at regular intervals and are reviewed regularly as their needs and circumstances change.⁽¹³³⁾

Consent should be given freely and without duress. The person using services must understand that they have a choice and are not under any pressures or threats imposed by others. It is important that the person using services has capacity to make the particular decision. Best practice favours a 'functional' or 'decision-specific' approach to defining whether a person has capacity to make decisions, for example it must be topic-specific and time-specific.⁽¹³³⁾

5.2.4 Decision-making processes in health and social care services

The Equality and Human Rights Commission in the UK states that a human rights-based approach provides an ethical framework for person-centred decision-making by ensuring that rights are only restricted where proportionate and necessary.⁽²³⁾ This approach places the individual at the centre of the decision-making process.⁽¹²¹⁾

The Assisted Decision-Making (Capacity) Act 2015⁽⁴⁸⁾ was signed into law in Ireland in 2015 but at the time of this report is not yet fully commenced. This Act applies to all adults and is relevant to all health and social care services. The Act is about supporting decision-making and maximising a person's capacity to make decisions. Health and social care professionals must start with the presumption that every adult using services has the capacity to make decisions about their care and support. A person is presumed to have capacity, for example, to accept or refuse an examination, investigation or treatment. This presumption applies irrespective of their age, disability, appearance, behaviour, medical condition, their beliefs or their inability to communicate without help, or because the decision which the person wants to take seems unwise to the health and social care professional.⁽¹³³⁾

Implementing supported decision-making requires giving those who may have difficulty making decisions the time and support they need to make a decision for themselves.^(133,134)

Effective decision-making requires a discussion between the person using services and the health and social care professional. It allows the person using services to have an opportunity to have their point of view expressed, listened to and weighed in relation to decision-making about their care and treatment. It is often the case that a decision can conflict with the rights of the person using services and the duties of the health or social care provider.⁽²³⁾ The 2015 Act requires that the healthcare professional gives effect to the person's past and present will and preferences as far as practicable. The healthcare professional must take into account the person's beliefs and values and any other factors which the person would be

likely to consider if able to do so. These must be balanced with the health and social care practitioner's knowledge, experience and clinical judgment.^(133,135,136)

The Assisted Decision-Making (Capacity) Act 2015 legislates for Advance Healthcare Directives. Effective Advance Healthcare Directives can already be made even though commencement of the 2015 Act is pending. An Advance Healthcare Directive is a formal record made when the directive-maker has capacity, to be used to inform family, friends and doctors of wishes for and refusals of treatment in the event that the directive-maker loses capacity. Any person aged 18 and over who has decision-making capacity can make an Advance Healthcare Directive. Currently, in the absence of a completed Advance Healthcare Directive, it is the medical team that will make these decisions. Good practice is also to consult with family and friends as to what the person's will and preferences would be in terms of treatment.⁽¹³²⁾

5.2.5 A human rights-based approach to decision-making

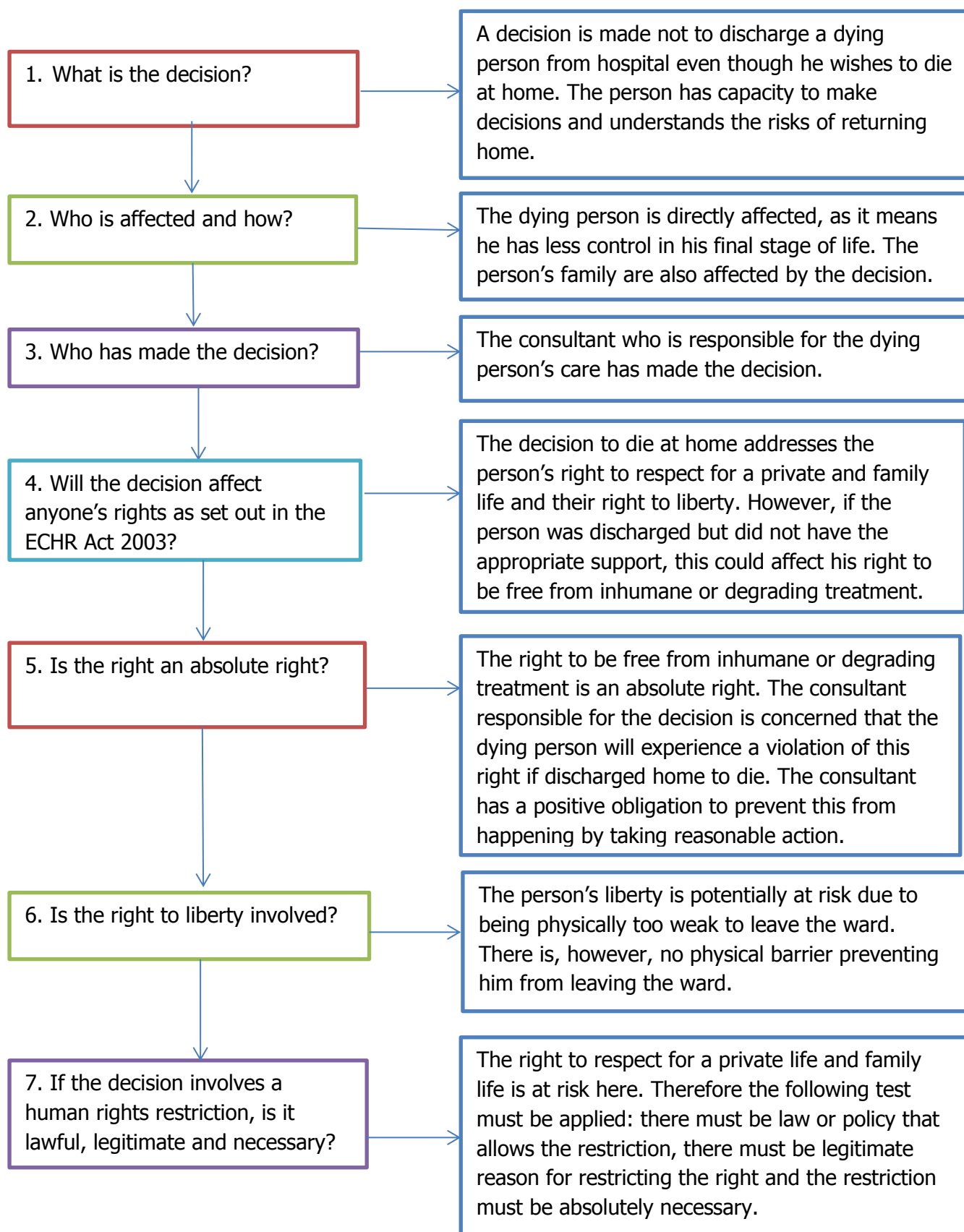
The literature included in this review emphasised the importance of decision-making processes based on the human rights of the person using services. By applying a human rights-based approach to decision-making, health and social care practitioners can weigh up the rights of the person using services while taking into account the risks which could affect the person's or other people's safety or wellbeing. Two processes for guiding health and social care providers through a human rights-based approach to decision-making include the Scottish Human Rights Commission's FAIR Approach⁽¹³⁵⁾ and the British Institute of Human Rights' Guidance for Practice.^(70,130,137,138) The Scottish Human Rights Commission sets out the FAIR Approach as follows:⁽¹³⁵⁾

- **Facts:** It is important to outline the experience of the person using services and to determine if the person is being heard. If the person is not being heard, it must be assessed if they require support. The service provider must establish the important facts that the person using services needs to understand.
- **Analysis of the rights at stake:** It is important to outline the human rights or issues at stake and if the right to life or the right not to be subjected to inhuman or degrading treatment is at stake. It must be acknowledged that these rights are absolute and cannot be restricted. If it relates to a different right, it must be established if the right can be restricted, if there is a justification for restricting the right and if the restriction of the right is proportionate, for example, is it the minimum necessary restriction to meet the aim?

- Identification of shared responsibilities: This is to set out what needs to be done and who has responsibility for doing it.
- Review actions: This establishes whether the actions taken have been recorded and reviewed and the individual affected has been involved.

The British Institute of Human Rights has developed specific decision-making flow charts.^(70,130,137,138) These address real-life examples that occur in different settings, for example inpatient rehabilitation units, maternity services and mental health units. An overview of the type of questions asked using this approach and the appropriate actions to respond to these questions is set out in Figure 6. An example is provided in Figure 6 that relates specifically to a situation that can arise in services for end-of-life care.

Figure 6: The British Institute of Human Rights decision-making flow chart



5.2.6 Confidentiality of personal information

Under a human rights-based approach to care and support, it is important to ensure that medical records and information about the treatment of a person using services are part of their private life, and any disclosure of this information should respect the person's right to a private life.^(74,122) While the service provider can expect to obtain and review a copy of a person's health information, this can only be accessed by those who need it for the provision of care and support. The person should be facilitated to complain if he or she is unhappy with how a service has used his or her personal information.⁽¹³⁶⁾ One article highlighting the importance of using personal information as a source for discussion and decision-making emphasises the importance of a person's private information being kept securely in medical records. It is important that medical practitioners exercise discretion on what is recorded.⁽¹²⁹⁾

5.2.7 Risk assessment

To ensure the principle of fairness is implemented in a service, it is important for health and social care services to have clear and consistent processes in place for risk assessment. Risk assessments should apply explicit criteria and form part of an overall assessment process.⁽¹²⁸⁾ Fair processes allow people using services to access information held about them regarding risk. They should also know in advance on what basis this information may be shared with others.⁽¹²⁸⁾ All decisions relating to risk involve balancing health and safety issues; they should also consider the person using services' quality of life, personal growth, rights and choice. One report, which looked at different ways to provide information about human rights to people with intellectual disabilities, discussed the importance of implementing positive risk management. The term 'positive risk management' in itself relates to building a culture within a service where risk management is openly discussed and proactively managed.⁽¹³⁹⁾

5.2.8 Restrictive practices

Restrictive practices are practices that intentionally limit a person's movement, communication or behaviour. The World Health Organisation (WHO) states that people must not be unlawfully or subjectively deprived of their liberty. It is important that any deprivation of liberty conforms with the law.⁽¹²²⁾ In the WHO's QualityRights toolkit,^{§§§§§§} the right to exercise legal capacity and the right to personal liberty and

§§§§§§ The WHO's QualityRights toolkit provides countries with practical information and tools for assessing and improving quality and human rights standards in mental health and social care facilities. The toolkit is based on the United Nations Convention on the Rights of Persons with Disabilities. It provides practical guidance on: i) the human rights and quality standards that should be respected, protected and fulfilled in both inpatient and outpatient mental health and social care facilities; ii) preparing for and conducting a comprehensive assessment of facilities; and iii) reporting findings and making appropriate recommendations on the basis of the assessment.

the security of the person are discussed. It recommends that people's preferences regarding the place and form of treatment they receive are always a priority. It also recommends that procedures and safeguards must be in place to prevent detention and treatment without free and informed consent.⁽¹²²⁾ A person's human rights are violated if they are prevented from leaving a residential care home or hospital without the procedural safeguards in place as set out in Ireland's Mental Health Act, 2001.⁽⁷⁴⁾

In relation to restrictive practices, health and social care practitioners can struggle to understand what makes a practice restrictive, and their legal, ethical and professional accountability in the use of these practices. This lack of understanding can contribute to the routine implementation of practices that practitioners do not realise are restrictive and possibly unlawful. A framework has been developed by the Royal College of Nursing in the UK to guide decision-making on restrictive practices using a rights-based approach.⁽¹⁴⁰⁾ The framework empowers health and social care practitioners to ask questions if they are not satisfied with an intervention, and to ensure adjustments are made. It also provides health and social care practitioners with the support and reassurance that any intervention used has been considered, planned and implemented legally and ethically. The three steps to the positive use of restrictive practices are:

- **Consider and plan:** The health or social care practitioner should consider if the planned intervention is a restrictive practice using the following definition: 'Restrictive practices are those that limit a person's movement, day-to-day activity or function.' The health or social care practitioner should consider other, less restrictive measures. They should also consider if the planned intervention is therapeutic in its intention.
- **Implement safeguards:** The health or social care practitioner should use a rights-based approach in professional accountability and legal frameworks to ensure that any restrictive practice is used only when it is in the person's best interests.
- **Review and reflect:** It is important that regular and timely review of the use of the restrictive practice is built into a therapeutic plan to meet the person's needs, including reduction and removal of the practice as soon as possible.⁽¹⁴⁰⁾

5.2.9 Making a complaint

It is important for services to ensure there is a strong and fair process for dealing with concerns about the professional conduct or performance of a health and social care practitioner or service. There must be procedures in place to hold the organisation to account for people using services who feel that their human rights

have been, or are in danger of being breached.⁽¹²⁴⁾ A service must be clear who is responsible for making sure that human rights are respected, protected and fulfilled.⁽¹²¹⁾ Evidence suggests that the health and social care complaints system can often be ineffectual, time-consuming and inaccessible.⁽¹²⁶⁾ A public engagement conducted by the Office of the Ombudsman^{*****} in Ireland with members of the public who had complained about a hospital service, reported that the main barriers to giving feedback or making a complaint was the lack of knowledge on how to make a complaint about a hospital service and the lack of awareness of the services available to do so.⁽¹⁴¹⁾ A fear of repercussions for their own or their relatives' treatment was reported in addition to a lack of confidence that anything would change as a result of complaining. A number of Irish reports^(125,141,142) have stressed the importance of ensuring that services create a supportive, open and transparent environment. It should be embedded within the culture of organisations to strive to lessen fear of there being negative consequences for making a complaint. People using services need to be supported in making a complaint and are entitled to have it investigated promptly and appropriately.⁽¹⁴³⁾

In 2015, the Office of the Ombudsman in Ireland published *Learning to Get Better*, which reported on the findings from an investigation into how hospitals handle complaints. The key findings from the investigation highlighted the need:

- to publicise information and supports available in order to encourage and assist people to share their experiences of hospital care
- to focus on learning (and sharing the learning) from complaints
- for senior managers to be active and visible in promoting and reinforcing a positive complaints culture within hospitals
- for the HSE to inform people (the public, hospital staff and the hospitals) on complaint outcomes which led to improvements and changes in procedures.

The report made a total of 36 recommendations to the HSE and the Department of Health. The recommendations were set out under the headings of Access, Process, Response, Leadership and Learning. The HSE and the Department of Health committed to implementing all recommendations. A progress report published in

***** The Office of the Ombudsman in Ireland was set up under the terms of the Ombudsman Act 1980, as amended by the Ombudsman (Amendment) Act 2012. The function of the Ombudsman is to examine complaints from members of the public who believe they have been unfairly treated by certain public service providers. The Ombudsman also examines complaints about failures by public bodies to provide accessible buildings, services and information, as required under Part 3 of the Disability Act 2005.

2018 noted that 10 of the recommendations have been implemented and a further 17 have been partially implemented.⁽¹⁴⁴⁾

In conclusion, Article 6 of the ECHR states that everyone has the right to a fair trial. In relation to health and social care services, this extends to processes that ensure the provision of accessible information, processes for obtaining consent, for ensuring confidentiality, for applying restrictive practices and for making a complaint. For these processes to be fair, people using services must be given the opportunity to have their views expressed, listened to and weighed. Implementing these processes allows others to determine how they might be treated in similar circumstances. Violations to fairness can occur if there is a lack of clear and fair processes in place for decisions to be made.

5.3 Principle 2: Respect

5.3.1 Introduction

Respect has been defined as 'the objective, unbiased consideration and regard for the rights, values, beliefs and property of other people'.⁽¹²⁾ Respect applies to the person as well as their value systems. Respect is construed from the actions shown to an individual by others and can be demonstrated by courteous communication, which instils the person with a sense of being valued through taking time to get to know them as individuals, not as "numbers" or "conditions"; it ultimately embodies person-centred care.⁽¹²⁰⁾ To uphold the principle of respect, people who use services must be valued as individuals, listened to, and what is important to them must be viewed as important by the service. Upholding the principle of respect means considering a person's views, wishes and feelings and ensuring that decisions, as much as possible, are in keeping with a person's wishes. The respect principle endures beyond any impairment or loss of capacity of the individual being offered care.⁽¹²⁰⁾ Upholding the principle of respect also means that a nominated person,[±] such as a family member or friend, is valued and listened to.⁽³²⁾

While dignity and respect are interrelated, some research has defined them separately in the following way: Respect relies on gaining and acting on the views of the person whereas people should be treated with dignity regardless of whether their views are known.⁽³²⁾

[±] A nominated person is a person who has been expressly identified by the person using the service and who has been given authority by that person as an individual with whom information in relation to them may be shared and who can assist them in making their views known. A nominated person can be a family member or another person who has an interest in the welfare of the person using the service. The involvement of any person must be in line with the expressed wishes of the person using the service.

In the ECHR, the principle of respect relates to Article 1, the right to peaceful enjoyment of possessions; Article 8, the right to respect for private and family life, home and correspondence; and Article 9, the right to freedom of thought, conscience and religion. Respect for private life can be interpreted to include personal choices, relationships, physical and mental wellbeing, access to personal information and participation in community life. The right to a private life encompasses confidentiality and privacy of medical information.⁽¹²⁰⁾

The following section will look at the key themes that emerged in literature relating to the principle of respect, including:

- ensuring respect is not denied
- promoting respect
- involving people who use services in service development.

5.3.2 Ensuring that respect is not denied

Denying a person any or all of their human rights can be seen as not upholding the principle of respect. One article looked at the experiences of people living with HIV and AIDS (PLWHA) of sexual health services.⁽¹⁴⁵⁾ Through the analyses of interviews with PLWHA, the findings show that stigma, discrimination, isolation and unequal power relations have an impact on PLWHA accessing services and their assertion of their sexual and reproductive rights. There was a lack of respect shown to PLWHA illustrated by a lack of access to appropriate information on their reproductive choices and reported pressure from health workers, family members and communities to not have children.⁽¹⁴⁵⁾

In a review of case law relating to sex and consent in vulnerable adults, the authors found that cases in this area raised the question of whether or not a person with intellectual disabilities could be afforded the same respect for their right to a private life as those who do not have intellectual disabilities.⁽¹⁴⁶⁾ While provisions are made under the law in England to protect vulnerable adults from potentially abusive relationships, case judgements pointed to the importance of respecting a person's right to a private life and allowing manageable or acceptable risks in order for this right to be respected and upheld.⁽¹⁴⁶⁾

One study in Norway examining the experiences people using mental health services found that in many instances an individual's rights had not been respected.⁽¹⁴⁷⁾ Examples included not being listened to regarding their diagnosis and not being informed regarding their treatment. Respondents also described how troubling life events they reported to healthcare practitioners were trivialised and ignored.⁽¹⁴⁷⁾

5.3.3 Promoting respect

Promoting respect is described in the context of primary care and medical education settings. Indicators and models of care are discussed that present the principles and requirements needed for treating people using services with respect and supporting them to live the life they choose. Finally, this section also sets out the importance for practitioners to not only treat people with respect but also to involve them in service development. By involving people using services in the design of quality services, decision-makers can understand how people are being treated and how they feel about the system in place.

5.3.3.1 Primary care

When individuals become vulnerable and are in need of healthcare services, privacy, dignity and respect are paramount in preventing further depersonalisation and a sense of loss of control.⁽¹⁹⁾ In discussing discrimination against people with learning disabilities, the author of an article published in *Primary Health Care* (2009) describes how primary care community professionals can improve practice in the care of this group and ensure a human rights-based approach is applied to all people engaging with primary care services in the community.⁽¹⁴⁸⁾ Respect is a key principle for health and social care practitioners working with people in community primary care. Respect for the individual can be demonstrated in how they are communicated with, listened to and understood as individuals. Primary care community practitioners are encouraged to:

- recognise and act on distress presented by individuals
- identify unmet physical needs
- develop an appreciation of what the personalisation and choice agenda means for people with learning disabilities
- become familiar with the specific health conditions associated with people with learning disabilities
- promote the right to appropriate services
- safeguard the needs of individuals in line with a duty of care
- make 'reasonable adjustments' to ensure capacity to consent to care or treatment methods is assessed (working in partnership with the individual, a family member and a key worker to do so)
- consider the unmet health needs of this group of people as a public health concern, supporting annual health reviews.⁽¹⁴⁸⁾

While the article related specifically to people with disabilities, the guidelines could be applied to all people using health and social care services.

5.3.3.2 Medical education

In an article on teaching human rights in medical education, the author outlines how a medical practitioner can show respect for the individuals they are treating. Described as a patient-centred approach, this includes understanding a person's wishes and values without judgement. The medical practitioner should show respect for a person's background, encompassing their life experience, educational attainment, literacy, culture, religious beliefs and, to an increasing extent, information acquired from the media and Internet. The person should be provided with accessible and relevant information and have their questions answered at a level they can understand. At the same time, the person should expect that their privacy will be respected and that their medical records will be kept securely. No person should be discriminated against based on personal characteristics.⁽¹²⁹⁾

5.3.3.3 Indicators and models of care

A number of studies have assessed ways respect can be measured in health and social care services. One study carried out in the UK, in which researchers aimed to develop dignity indicators for older people, highlighted the interconnectedness of dignity and respect and showed how respect could be shown to people using services.⁽¹⁴⁹⁾ Indicators for respect include:

1. respectful delivery of care and support
2. knowledge of and respect for an individual's preferred lifestyle (including routines, pets, clothing preferences, religious and cultural preferences)
3. respect for property and possessions.⁽¹⁴⁹⁾

A paper looking at a human rights-based approach to working with people with intellectual disabilities and behaviours that challenge demonstrated the effectiveness of the multi-element behaviour support (MEBS)* model in meeting these rights.⁽¹⁵⁰⁾ It does this through explicitly linking the multi-element model to the guiding principles of a human rights-based approach. Using this model, the person is treated

* The multi-element behaviour support (MEBS) model is an approach that recognises that difficult behaviour is a language used by people who do not have any other way to communicate their message. The behaviour becomes unnecessary when the behaviour finds a voice. MEBS is based on a two-part assessment that involves 'getting to know the person' and 'getting to understand the behaviour'.

with dignity and respect and supported to live the life they choose to live. The principles, defined by how they relate to the MEBS approach, are as follows:

- **Express link to rights:** This involves the service identifying and naming the rights that the person may not be in a position to exercise.
- **Participation:** This involves the service identifying barriers that exist which limit the person in terms of exercising rights.
- **Empowerment:** The service explores how the person can be empowered through the selection of appropriate interventions.
- **Non-discrimination:** The service ensures that persons with disabilities and behaviours that challenge are not discriminated against on the grounds of their disabilities or behaviour.
- **Accountability:** This involves the service using an evaluation tool to monitor if the person is receiving the service they require.

Finally, at the time of this report, a national framework for person-centred planning in services for people with disabilities is being introduced by the National Disability Authority.^(151,152) Person-centred planning presents the principles and requirements needed for treating people using services with respect, and is a way of helping people to think about what is important to them, how they want to live and what support they want. Each person should have a person-centred plan that is entirely unique to them, reflects their hopes and dreams and aims to support them to achieve their goals. Person-centred planning aims to move away from focusing solely on a person's disability and trying 'help' or 'fix' them, to appreciating the person and allowing and supporting them to live their lives according to their wishes.⁽¹⁵¹⁾⁺⁺⁺⁺⁺⁺

5.3.4 Participation in service development

The literature shows that promoting respect is not just about healthcare practitioners treating people using services with respect; it also means ensuring that people who use services participate in service development.^(120,145,153)

People should not be treated as passive recipients of goods and services, but rather as participants in decisions that affect their wellbeing. A document published by the Department of Health in England proposed that feedback from patients on a doctor's performance should form part of the process of relicensing doctors. Suggested areas

++++++ In 2019, the HSE plans to implement the person-centred planning framework in four disability day service provider organisations and review and evaluate the process with a view to wider application.

for patient feedback included the doctor's communication skills, their involvement of patients in decision-making and their treatment of patients with respect and dignity.⁽¹⁵⁴⁾

The author of an article on promoting a human rights-based approach to recovery in mental health practice^{*****} underlines the importance of showing respect for a person by ensuring they are involved in discussions about their health. Respect can be shown by not using technical language to describe the condition but by using the person's own words instead. This approach shows respect for a person's thoughts and belief systems and supports them in accessing their human rights.⁽¹⁵⁵⁾

In their work, the International Community of Women Living with HIV (ICW) and the Global Network of People Living with HIV (GNP+) have maintained that it is the HIV-positive women, children and men who access (or not) and depend (or not) on healthcare services who can most convincingly evaluate whether a clinic and its healthcare providers are delivering the kind of HIV testing, care and treatment services they actually need.⁽¹⁴⁵⁾

The United Nations High Commissioner for Human Rights' guidance, entitled 'Technical guidance on the application of a human rights-based approach to the implementation of policies and programmes to reduce preventable maternal mortality and morbidity',⁽¹⁵⁶⁾ makes clear that human rights principles of non-discrimination and equality, transparency, participation, and accountability should inform the design, organisation and coordination of the WHO's six components of the health system (service delivery; health workforce; information; medical products, vaccines, and technologies; financing; and leadership and governance). It also emphasises that women are not passive beneficiaries; they are active rights holders who are entitled to take part in a meaningful way in discussions on matters that relate to their sexual and reproductive health.

In an evaluation of a mental health facility, researchers found that people using the services suffered discrimination, inequality and lack of recognition of their legal capacity. The authors submit that patients should be involved in the design of quality healthcare services that comply with international law. They highlighted the importance of stakeholders understanding how the patients are being treated and how they feel about the system in place.⁽¹⁷⁾

To conclude, respect underpins all human rights and overlaps with the principle of dignity. Violations of respect often occur when a person's human rights as laid out in

^{*****} Recovery in the mental health context has been described as the process of changing one's attitudes, values, feelings, goals, and skills in order to live a satisfying life within the limitations caused by illness.

Articles 1, 8 and 9 of the ECHR are not upheld. A key element of promoting respect in health and social care settings is recognising and understanding a person's needs and personal preferences without judgment. Appropriate communication, non-discrimination, and ensuring the participation of people using services in the evaluation and development of services can also help to promote respect in health and social care settings.

5.4 Principle 3: Equality

5.4.1 Introduction

Equality can be defined as individuals or groups having equality of opportunity, and being treated equally and no less favourably than other individuals or groups on different grounds set out in equality legislation.⁽¹⁵⁷⁾ Article 7 of the Universal Declaration of Human Rights (1949) recognises that all people are equal before the law and are entitled without any discrimination to equal protection of the law. This provision promotes an autonomous, free-standing right to equality before the law and equal protection of the law.⁽¹⁰⁾ In Ireland, the Equal Status Acts 2000-2015 are key laws relating to equality in the provision of goods and services, accommodation and education. In relation to the provision of goods and services, the Equal Status Acts aim to promote equality and ban certain types of discrimination across nine grounds: sex, civil status, family status, sexual orientation, religion, age, race, membership of the Traveller community and disability.^{§§§§§§§§} If a health or social care organisation provides any goods, facilities or services to the public or a section of the public, it must adhere to the equality laws.⁽¹⁵⁸⁾ The Equal Status Acts aim to allow a broad range of positive actions which promote equality of opportunity among people who may need extra help.⁽¹⁵⁷⁾ There are many features of the principle of equality and these overlap with the principle of respect.⁽¹²⁰⁾

This section first sets out how equality is protected under the European Convention on Human Rights and explains the different types of discrimination and how these can affect a person's other rights. Equality in health and social care settings will then be discussed under the following headings:

- Equality of access to care and support
- Equality of outcomes from care and support

^{§§§§§§§§} The Equal Status Acts prohibit discrimination in the provision of goods and services, accommodation and education. In relation to the provision of accommodation, the Equality (Miscellaneous Provisions) Act 2015 created a 10th ground in respect of housing assistance where discrimination in the provision of accommodation services against people who are in receipt of rent supplement, housing assistance, or social welfare payments is prohibited.

- Supporting participating in society⁽¹⁵⁹⁾

The promotion of equality in practice and the importance of training staff will also be discussed. Finally, an overview will be provided on measuring equality and the experience of people using services.

5.4.2 Equality and the European Convention on Human Rights

The European Convention on Human Rights (ECHR) states that human rights cannot be breached or enforced differently because of a person's sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or any other status. Article 14 protects against discrimination on a wide range of areas because it includes 'any other status'. This means it is a special right, because it states that a person cannot be discriminated against in connection with any of their other rights set out in the ECHR.

There are different types of discrimination and these can impact on a person's other rights.^(70,137,138) An action or decision is considered discriminatory if it cannot be reasonably and objectively justified. It can occur when someone is treated in a different way to someone else in a similar situation, or where people in very different situations are treated the same. Non-discrimination and equality are key measures required to address the social factors affecting the enjoyment of the right to health.⁽¹⁶⁰⁾ Types of discrimination include: direct discrimination, indirect discrimination and discrimination by association. Poor care and support in a health or social care setting can lead to discrimination in these areas.

- **Direct discrimination** happens when a person is treated less favourably than another person in the same situation under any of the grounds covered by the ECHR, for example sex, race, colour, religion, language, political or other opinion, national or social origin, association with a national minority, property, birth or any other status. For example, this would occur if a Muslim man in a home care setting did not receive halal meals but his Jewish neighbour received kosher meals from the same home care agency. The Muslim man is being discriminated against in the enjoyment of his right to practice his religion and this violates Article 9 of the ECHR.
- **Discrimination by association** can occur when a person is treated less favourably simply because they are associated with or connected to another person. An example of this would be if a decision is made to delay the discharge of a person with a drug addiction from hospital because they associate with other people with drug addictions. This discriminates against a person's right to freedom as protected by Article 5 of the ECHR.
- **Indirect discrimination** happens when someone is treated in the same way as others without taking into account that person's different situation. The individual or group of people are placed at a disadvantage as a result of blanket policies, conditions or rules which they might find hard to satisfy as a result. For example, indirect discrimination can occur if activities or services are unsuitable or difficult for older people to access, or if older people are prevented from accessing them because of their age.

5.4.3 Equality of access to care and support

The literature highlights how human rights are currently being breached in relation to access to care and support on account of a person using services' status. Studies have reported that people using services often do not access care and support services and they have attributed this to their disability, age and health status.^(74,122,126,131,145,148,161)

A guide developed by Age UK⁽¹⁶¹⁾ reported that older people may be at a disadvantage because of their age. This can result in a lack of access to services, such as life-sustaining medical treatment. Research has found that 46% of GPs and specialists in the care of older people and 48% of cardiologists treated patients aged over 65 years differently from younger patients. Those over 65 years were less likely to be referred to a cardiologist, given an angiogram or given a heart stress test.^(74,161) Similarly, for people with disabilities and for people with mental health problems, discrepancies were reported in terms of not receiving standard, evidence-based healthcare checks and treatments such as health screening or statin

treatment.^(122,126,148) A report by a UK-based charity, Mencap, that works with people with a learning disability, found the most extreme form of denying treatment can be in the form of 'do not resuscitate' notices or the failure to make life-saving interventions. This report found evidence of doctors making value judgments about the quality of life of people with profound and multiple learning disabilities, in assuming that it would be in their best interests to die.⁽¹²⁶⁾ Access to care and support was also reported in relation to a person's health status. In an article looking at the experiences of sexual health services of people living with HIV and AIDS, it was found that stigma, discrimination, isolation and unequal power relations impact their accessing services and their assertion of their sexual and reproductive rights.⁽¹⁴⁵⁾

5.4.3.1 Ensuring equality of access in health and social care settings

A human rights-based approach can help health and social care providers to take positive steps to make it easier for people to access the physical and mental health care they need. One UK paper describes equality as when 'persons with disabilities are treated "on an equal basis" with those without; for example, the "will" of a person with a mental disorder is to be respected in the same way as the "will" of a person with a physical disorder.'⁽¹³¹⁾

Each member of staff working in health and social care services has a responsibility, relevant to their own role, to ensure that services are accessible, and that their interactions and communication with people are appropriate, respectful and delivered in ways that all people using services can receive and understand.⁽¹⁶²⁾

People who face the biggest barriers to realising their rights should be prioritised by health and social care services. A human rights-based approach means paying particular attention to the protection and realisation of their rights.^(148,163) In a report by Mencap, recommendations were made to ensure services respect the equality of people with a learning disability. The recommendations included:

- having longer-length appointments for people with a learning disability
- having accessible information provided in all healthcare settings
- for screening programmes to ensure that people with a learning disability have the same access rate as others
- identification on health records that a person has a learning disability
- for hospitals to provide appropriate levels of support to patients with a learning disability.⁽¹²⁶⁾

5.4.4 Equality of outcomes from care and support

Life expectancy for people diagnosed with certain mental health issues can be up to 20 years lower compared to the general population.⁽⁶⁹⁾ An assessment by the WHO on the quality of institutional care for adults with psychosocial and intellectual disabilities in the WHO European Region, found that no discrimination against individuals was observed on the basis of race, ethnicity or religion within the facilities. People using the services did, however, report some discrimination when they sought medical treatment outside their facility.⁽¹⁶⁴⁾ It was felt that healthcare providers did not treat participants kindly because of their mental and psychosocial disabilities.⁽¹⁶⁴⁾ It is difficult to determine to what extent such experiences can be explained by a lack of understanding and training among healthcare practitioners. However, there is a body of opinion that it could be due to discrimination by healthcare staff involving value judgments about the worth of people with a learning disability.⁽¹²⁾

Lack of equality of outcomes from care and support has also been recognised in older populations. Age UK reported evidence of discrimination of older people in social care services with the expenditure per week on older people receiving social care being lower than other age groups. One reason for this is that the social care assessment process for older people can be rushed compared to younger people, particularly in the context of hospital discharge. It was also reported that assessments for older people are generally narrower in scope and focused on physical needs.^(74,161)

5.4.4.1 Ensuring equality of outcomes in health and social care settings

An Irish report assessing LGBTI health needs and experiences reported the need for services to be organised on the basis of promoting equality. This means acknowledging and accommodating difference rather than treating everyone the same.⁽¹⁶⁵⁾ Additionally, a review of adult social care services highlighted the need to recognise that although everyone has a shared set of rights, different groups – for example people with disabilities – may have additional needs.⁽¹⁶⁶⁾ It is important for services to provide additional supports for certain groups to ensure their needs are met.

Good practice is when organisations tell the person using the services about their equality policy, or other ways they set standards for their staff so that they do not discriminate against people. Service providers' behaviour towards people using services is very important. A health or social care provider can also tell the person using the service what standards of behaviour they expect from them as a person using services, patient or client; this includes behaving with respect towards their staff and towards other people using services. If a health or social care provider sets

standards of behaviour for people using services that have a negative impact on people with a particular protected status, the provider needs to make sure that they can objectively justify what they have done. Otherwise, it will be indirect discrimination.⁽¹⁵⁸⁾

Front-line staff should seek to resolve, at all times, concerns and queries from patients and people using services at the first point of contact with the person using services or their nominated person. Senior managers have a responsibility to support and promote the provision of accessible services for all people using services. All health and social care management should aim to ensure that the capacity of the service is developed to fully support people with disabilities in mainstream health services.^(148,162)

5.4.5 Supporting participation in society

Equality is about 'creating a fairer society, where everyone can participate and has the opportunity to fulfil their potential'.⁽¹⁶⁷⁾ Article 19 of the United Nations Convention on the Rights of Persons with Disabilities states that people with disabilities have the right to live in the community and that governments must take effective, appropriate measures to facilitate their full inclusion and participation in society.⁽⁴⁶⁾ Significantly, Article 19 states that people must be given access to a range of in-home, residential and other community support services, including the personal assistance necessary to support living and inclusion in the community, to prevent isolation or segregation. The concepts of inclusion and participation outlined in Article 19 are further articulated in other articles of the Convention, including those on the rights to education, to work and employment and to participation in political, public and cultural life and in recreation, leisure and sport.⁽¹²²⁾

A lack of promoting opportunities to participate in and contribute to society was reported in the literature; such a lack can lead to social exclusion.^(74,161) In a report by the Health and Social Care Alliance Scotland (2017), it reported that many people who have a disability or who live with long-term conditions feel less valued than their peers.⁽⁸⁹⁾ A Greek study assessing the quality of healthcare offered by a Greek public psychiatric clinic⁽¹⁶⁸⁾ reported that people using services were not considered equal before the law and were considered to have both functional and legal incapacities. People using these services were segregated and deprived of equal opportunities to others; they experienced barriers to full participation in society due to people's attitudes and the physical structures in their environment.⁽¹⁶⁸⁾ A Norwegian study has highlighted that in recent years research has focused on the gap between human rights objectives and the actual experiences of a people using services. It is important that this gap is not accepted simply because a person has a mental illness. It is important that people using mental health services as well as

other people have the right to express their needs, influence their treatment and be regarded as equal participants in society.⁽¹⁴⁷⁾

Two studies reported that people with intellectual disabilities experience wide-ranging rights violations and discrimination, which prevent them from living and being included in the community.^(122,169) It was reported that people were objectified in services which in turn led to dehumanisation, meaning that their experience differed significantly from that of mainstream society.⁽¹⁶⁹⁾ Both studies found that people were denied opportunities to work and get an education and access the social and financial support they required to live in the community. They were also restricted in joining and participating in political, religious, social and self-help or advocacy organisations. They were unable to exercise their religious or cultural practices and were denied opportunities for leisure, fitness and sports activities.⁽¹²²⁾ The studies state that this could be attributed to services focusing on treatment and care rather than on providing or facilitating access to the full range of support to allow people to live independently in the community and participate fully in society.⁽¹⁶⁴⁾

5.4.5.1 Health and social care services ensuring full contribution in society

A human rights-based approach to care and support views people as subjects rather than objects; they are seen as equal citizens and stakeholders in society. The human rights-based approach to care and support challenges the 'social impulse to rank people in terms of their usefulness and to screen out those with significant differences'.⁽¹⁷⁰⁾ It is important for services to 'treat people as adults, rather than putting or keeping them in dependent and unequal relationships'.⁽¹⁶⁶⁾ It must not be presumed that a person using services lacks capacity solely because of their age, disability, appearance, behaviour, medical condition, their beliefs, their apparent inability to communicate, or because their decision seems unwise to the health and social care practitioner.⁽¹³³⁾

Health and social care services, if developed and delivered in a human rights-based way, help ensure that everyone can live their life the way they choose, at home, at work and in the community. A human rights-based approach is a critical tool to enable people to contribute as active citizens, creating an inclusive and equal society. It is not just about individual rights, but taking a wider 'rights-based' approach that values the qualities that people who are disabled and people who live with long-term conditions have to offer.⁽⁸⁹⁾

5.4.6 Promoting equality in practice and training staff

The literature recommends that equality training be provided to health and social care practitioners.^(126,158,165) This has been specifically emphasised in relation to

services supporting older people, people with disabilities and people from the LGBTI community. It is important that increased training and development of knowledge and skills within services be provided to ensure appropriate, timely and professional access to and delivery of health services. Specifically for people with intellectual disabilities, staff should receive general disability awareness training so that they have the opportunity to examine their attitudes and values towards people with a learning disability.⁽¹²⁶⁾ An Irish report into the experience of healthcare services by people from the LGBTI community recommended that training modules and information be developed and provided to build understanding of the particular needs of LGBTI people in these service areas. Privacy, confidentiality and the sexual practices of LGBTI people should be part of the training and information content for sexual health service providers.⁽¹⁶⁵⁾

In the area of educating healthcare practitioners on human rights, two articles described how discrimination can be challenged and equality principles can be applied to the education and training of healthcare practitioners.^(171,172) In order to build knowledge, change culture and empower advocacy, equality principles must be discussed with students as openly as possible within an institution and students must know where to go when concerns about discrimination arise.⁽¹⁷²⁾

5.4.7 Measuring equality and the experience of people using services

The literature^(161,173) suggests a number of recommendations to measure equality within a service. Taking steps towards equality involves first identifying unequal outcomes. Health and social care providers must understand what barriers people using services face and make sure that they directly engage with people to understand their needs and views.^(161,173) To help organisations conduct internal audits and review their approaches to human rights and equality, the Irish Human Rights and Equality Commission has developed a set of questions to identify strengths and weaknesses.⁽¹⁷³⁾

The audit asks if the organisation:

- is aware that when equality of people using services is invested in, this can benefit the organisation
- has ever taken action to find out the equality needs of the people using the service
- has ever engaged with organisations representing people using services from across each of the equality grounds to find out the equality needs of people using services
- has ever identified any barriers preventing people from accessing the service

- has feedback mechanisms in place to enable people using services from across each of the equality grounds to rate the service
- has ever considered if the service complies with the Equal Status Acts 2000-2015
- has an equal status policy outlining the service's commitment to equality for people using the service.⁽¹⁷³⁾

Two articles recommend that an equality impact assessment be conducted to help organisations make sure that their policies and practices are meeting their objectives without having unintended consequences for certain groups.^(161,173) When an impact assessment is conducted, people using services should be actively engaged with to identify if a policy or practice has an adverse impact on specific groups. Steps must then be taken to reduce or eliminate any adverse effects. It must be made clear who is responsible for ensuring that these steps are taken and within what time frame.^(69,161,173)

In relation to day-to-day practices within a health or social care environment, the British Institute of Human Rights^(62,69) recommends asking the following three questions before making a decision that may restrict a person's right to non-discrimination against any other rights:

- Is the decision lawful? There must be a law that allows this restriction.
- Is there a legitimate aim? There must be a legitimate reason for restricting this right. These reasons are written out in the right itself and include the need to protect the rights of others or the wider community.
- Is it necessary? The least restrictive action necessary to achieve the aim must be taken. The key principle here is proportionality.^(62,69)

Finally, a good-practice guide developed by Inclusion Ireland provides information on the set-up, running and reviewing of Equality and Rights Committees. It is recommended that every disability service should have an Equality and Rights Committee. Among the functions of the committee is to develop equality and human rights statements for the specific service, to examine policies and practices in the service against the equality and human rights statement, and to support and encourage a culture that promotes the values of equality and human rights within the service.⁽⁹⁾

To conclude, under Article 14 of the ECHR, people using health and social care services must be guaranteed equal treatment in the enjoyment of their other rights as set out in the Convention. The principle of equality overlaps with the principle of

respect. It also relates to non-discrimination. As discussed in section 5.4.2, there are three main types of discrimination and a person can be discriminated against for many reasons. To ensure the principle of equality is not violated, people using services must have equal access to care and support; they must have equal outcomes from care and support; and they must be supported and have equal opportunity to participate and contribute fully in society.

5.5 Principle 4: Dignity

5.5.1 Introduction

Dignity is central to the idea of rights and all human rights are connected to human dignity.⁽³⁴⁾ The Oxford English Dictionary defines dignity as 'the state of being worthy of honour or respect' or 'high regard or estimation'. The 1948 Universal Declaration of Human Rights and Article 1 of the Charter of Fundamental Rights of the European Union recognise dignity as a human right.⁽¹⁷⁴⁾ It is important that public authorities use human rights as a way to improve services by making the principles of dignity and respect central to their policy agenda, and placing people using services at the heart of what they do.⁽²⁹⁾

In a health and social care context, the Care Quality Commission in the UK considers dignity to be upheld where people who use services are always treated in a humanitarian way – with compassion and in a way that values them as human beings and supports their self-respect, even if their wishes are not known at the time.⁽³²⁾ Dignity is often mentioned in definitions of harassment, for example, the Equality and Human Rights Commission in the UK defines harassment as 'unwanted behaviour that has the purpose or effect of violating a person's dignity or creates a degrading, humiliating, hostile, intimidating or offensive environment'.⁽¹⁵⁸⁾ Lack of dignity is often central to human rights abuses in health and social care and a lack of dignity is a common theme in the examples of abuse and neglect including malnutrition and dehydration; physical, psychological or sexual abuse; ignoring calls for help; unchanged sheets; not feeding people properly; bed sores; poor hygiene; excessive physical restraint; and bullying, patronising and infantilising attitudes.⁽¹⁷⁵⁾

Respect for the fundamental dignity of each person is an important measure of success for health and social care services.⁽¹⁶³⁾ Dignity in care means care which supports and promotes, and does not undermine, a person's self-respect.⁽¹²⁾

Research with people using services and health and social care staff identified the issue of supporting and preserving the dignity of people using services as the most fundamental aspect of care.⁽¹⁷⁶⁾ A review study showed that when human dignity is maintained in health and social care settings, it improves working relationships and results in appropriate decision-making and professional behaviour.⁽¹⁷⁷⁾ On the other hand, if dignity is not preserved, it results in feelings of insecurity, guilt, shame,

worthlessness, anger, frustration, lack of confidence, inadequacy and reduced motivation, reduced quality of patient care, and decreased satisfaction among staff.⁽¹⁷⁷⁾

A European programme (including participants from Spain, Slovakia, Ireland, Sweden, France and the UK) found that there was agreement about the meaning and experience of human dignity, and that dignity involved: respect and recognition, participation and dignity in care. On the other hand, loss of independence, fear of becoming a burden, not being involved in decision-making, lacking access to care and some attitudes of staff were identified as harming participants' sense of dignity.⁽¹⁷⁴⁾

This section discusses dignity under the following headings:

- The relationship between dignity, privacy and respect
- Dignity and the European Convention on Human Rights
- Dignity and communication
- Dignity and personal freedom
- Promoting dignity in practice and training staff
- Measuring dignity and 'patient experience'

5.5.2 The relationship between dignity, privacy and respect

The concepts of dignity, privacy and respect are interrelated, and when individuals become vulnerable and are in need of health and social care services, privacy, dignity and respect are paramount in preventing further depersonalisation and a sense of loss of control.⁽¹⁷⁸⁾ Some definitions consider respect and privacy as components of dignity; others define them separately.⁽¹⁷⁸⁾ In a health or social care setting, privacy could be seen as the exposure of an individual's body but it also encompasses confidentiality, for example staff not discussing issues about people using services in inappropriate places.⁽¹⁷⁸⁾ Protection of patient confidentiality and privacy of patient information includes that, during ward rounds and examinations or other interactions between staff and patients, the personal information of patients does not become public knowledge to anyone else in the bay.⁽¹⁷⁹⁾ Respect in this type of setting includes people using services being paid attention to and having their individual needs met.

Some research considers the difference in definitions of respect and dignity to be that respect relies on gaining and acting on the views of the person, whereas people should be treated with dignity regardless of whether or not their views are known.

For example, someone who arrives at the emergency department in an unconscious state should still be treated with dignity,⁽³²⁾ and the principle of dignity must be upheld even after death, for example, by having proper procedures in place to regulate the retention of human tissue after a post-mortem.⁽¹²⁾

A report by the Equality and Human Rights Commission (the Commission) in the UK found that participants reported a complete disregard for their privacy when home care workers were supporting them to undress, bathe and dress. This lack of respect for privacy seems to stem from workers or their managers not thinking about the older person as an individual who needs to be accorded dignity and respect for their personal privacy.⁽²³⁾

One male respondent aged over 65 said:⁽²³⁾

‘There is a constant parade of new staff passing through the house, to be “trained”. [My] personal dignity is not respected. “Trainees” turn up unannounced and the agency fails to contact us beforehand to ask permission. I have MS and am very severely disabled, and feel my dignity when being showered and dressed is not being respected when I have several trainees observing quite an intimate routine.’⁽²³⁾

People’s dignity can also be infringed upon when staff have to rush tasks that intrude on personal privacy, such as staff performing intimate care tasks in a distracted and rushed way, without having time to talk to individuals about how they would like care tasks to be carried out.⁽²³⁾ Evidence suggests that it may be difficult for providers to adopt a human rights-based approach to home care unless the problem of time constraints can be addressed.⁽²³⁾ The report by the Commission concludes that many affronts to dignity stem from issues that are easily fixed, such as covering someone with a towel while washing them.⁽²³⁾

In Ireland, the HSE’s National Healthcare Charter⁽¹⁸⁰⁾ states, ‘We will treat you, your family and carers with dignity, respect and compassion. We respect diversity of culture, beliefs and values in line with clinical decision making. Please treat staff with dignity respect and consideration.’

In terms of dignity, the charter outlines that people using services can expect:⁽¹⁸⁰⁾

- care that respects one’s culture, beliefs, values and other characteristics such as one’s age and gender, sexual orientation, faith, political beliefs or disability and is in line with clinical decision-making
- care that is provided in a sensitive, kind and compassionate way

- end-of-life care that is dignified, comforting and supports relief from suffering.⁽¹⁸⁰⁾

The charter also suggests ways that people using services can help promote dignity and respect in all healthcare services by:

- treating healthcare staff politely and with respect and consideration – physical, racial, sexual or other kinds of harassment or abuse are unacceptable
- showing consideration for patients in hospitals who may need time to rest and recover by adhering to hospital visiting hours.⁽¹⁸⁰⁾

5.5.3 Dignity and the European Convention on Human Rights

In terms of the relationship between the concept of dignity and the European Convention on Human Rights (ECHR), Article 3 of the ECHR prohibits torture and inhuman or degrading treatment or punishment. The European Court of Human Rights has set a high threshold before particular cases can be considered to violate Article 3.⁽¹²⁾

Poor care that could engage Article 3 issues could be anything from physical abuse, excessive restraint and neglect to malnutrition and dehydration resulting from unintentionally leaving meal trays out of reach of patients.⁽¹²⁾ Poor care can have an impact on a person's right to be protected from inhuman or degrading treatment whether or not it arouses feelings of fear, anguish or inferiority in the victim. Inhuman or degrading treatment towards a person can also be identified by others whether or not the person themselves is too ill and or lacks capacity to judge the situation.⁽¹⁸¹⁾ An NHS report on human rights in healthcare highlighted that there is a need for policy or practice change to ensure individuals are protected against torture and inhuman or degrading treatment. For example, it is important that services ensure there are sufficient staff to promptly change wet sheets to reduce the risk of people suffering degrading treatment.⁽¹⁸²⁾

In clinical settings, environmental shortcomings can also have an impact on a person's dignity, for example having a lack of privacy in mixed-gender wards or having to live in impoverished, unclean or dangerous environments. Failures to meet standards of dignity and privacy may amount to violations of the right to respect for private and family life under Article 8 of the ECHR.⁽¹²⁾ Bathing a person or assisting them to the toilet without regard for their privacy or dignity may in some circumstances also amount to a breach of their right to respect for private life.⁽¹⁸³⁾

Some human rights issues are relevant to more than one article, depending on the degree of the breach. For example, neglect that compromises someone's dignity

may be a breach of Article 8 or (if the neglect is very severe) Article 3, in relation to the prohibition on inhuman or degrading treatment.⁽³²⁾

5.5.4 Dignity and communication

Research with people with experience of detention in psychiatric institutions across 15 European countries found that a critical issue was the quality of contact with doctors, nurses and other staff.⁽¹⁸⁴⁾ The majority of participants saw personal relationships with staff in psychiatric institutions as a high-priority area when thinking about human rights. Across the sites, the unwillingness of staff to engage with patients was experienced as degrading and a denial of patients' humanity, as evidenced in the below quotes from participants in Finland, Austria, Italy and the UK, respectively:⁽¹⁸⁴⁾

'In view of human rights, so that the patient could feel empowered, it is necessary to have continuous and regular interaction. So if the staff is, sort of, away from the ward in their own rooms and cubicles, and do not engage in continuous interaction with the patients—that it is a kind of violation against their human dignity as if there were sort of two different castes. In a way this is expression of humiliation.'⁽¹⁸⁴⁾

'Myself, for example, I managed to be admitted to the hospital in [place] five times without ever being asked how I am.'⁽¹⁸⁴⁾

'They worked but they didn't speak to us.'⁽¹⁸⁴⁾

'Close observation has replaced interaction you know, that's the thing.'⁽¹⁸⁴⁾

Another study of patient dignity in psychiatric settings found that patients' dignity was perceived to be upheld when nurses were able to connect with patients and allow themselves to be moved by patients' stories.⁽¹⁸⁵⁾ The link between active listening and upholding dignity has also been highlighted in disability settings. For example, Inclusion Ireland states that services should treat people with intellectual disabilities with dignity and respect and that interactions should be accessible, friendly and respectful, involve listening, and be timely.⁽¹⁸⁶⁾

Further research conducted in the UK indicates that staff (in this case, nurses) do not always communicate with patients in a way that indicates their individuality is respected. Patients' individuality, dignity and personal identity can be compromised by the way staff address them using their first name without their consent and in an endearing manner (using words such as 'love' and 'darling'). However, it was noted that the majority of medical staff addressed patients with respect, usually calling them by their surnames or 'sir' or 'madam'.⁽¹⁷⁹⁾

5.5.5 Dignity and personal freedom

In the context of mental health care, dignity is important to all individuals with mental disorders and not just the minority who are subjected to involuntary detention and treatment.⁽³⁴⁾ Occasionally, however, a person's freedom may appear to be in conflict with their dignity.⁽¹⁸⁷⁾ In Ireland, the Mental Health Act, 2001 imposes a certain duty on mental health services and the Gardaí to protect and restore the dignity of individuals by having regard for their dignity, rights and welfare when making decisions in relation to them. However, some researchers argue that this is limited by the fact that the overarching principle of the legislation is 'best interests' rather than dignity itself and argue for the incorporation of dignity as the overarching principle in Irish mental health legislation.⁽³⁴⁾ This may be useful due to its clear meaning in situations in which the individual has full insight and capacity, and in situations where the individual's insight and or capacity may be impaired.⁽³⁴⁾ This would mean that practitioners, mental health tribunals and courts would have to explicitly consider the effects of their decisions on the dignity of patients, weighing up the indignity of untreated illness against the dignity-related implications of involuntary treatment. It would also create an incentive for treatment to be offered in a fashion that explicitly prioritises dignity, an approach which would be best advanced through the provision of effective, efficient treatment in a respectful and dignified manner, on a voluntary or involuntary basis.⁽³⁴⁾

5.5.6 Promoting dignity in practice and training staff

Adequately skilled, competent and empathetic health and social care staff are an important component of assuring good-quality health services.⁽¹⁸⁸⁾ Spending time with people using services is important, but this is not easy to measure in the performance targets set by healthcare funders. As a result, time, dialogue, compassion and empathy can be devalued. Research points to the types of attitudes, behaviours, compassion and dialogue that could be adopted and form the basis for teaching and providing care and support in health and social care settings, both in the community and in acute settings.⁽¹⁷⁴⁾ For example, Chochinov's ABCD (attitudes, behaviours, compassion and dialogue) framework for dignity-conserving care could be taught to practitioners entering health and social care professions.⁽¹⁷⁴⁾

Resources have been developed to support nurses and nursing teams to deliver care that supports dignity, humanity and equality including the Royal College of Nursing Diversity Toolkit and the associated Diversity Champions Programme in the UK.⁽¹⁷⁶⁾ The toolkit was designed to support nurses and healthcare assistants in improving their personal practice and confidence in diversity, equality and human rights issues in healthcare.⁽¹⁷⁶⁾ It provides up-to-date information on equality and human rights legislation in England, Scotland, Wales and Northern Ireland and information on a

wide range of resources dealing with domestic abuse, female genital mutilation, implications of faith for nursing practice and guidance on human rights issues around disability and migrant communities. The toolkit also provides information on communication styles.⁽¹⁷⁶⁾

A study of dignity indicators for older people in care found that indicators might include:

- support to maintain personal standards
- respectful delivery of care and support
- timetabling of services to suit the client
- consistency of care workers
- knowledge of and respect for an individual's preferred lifestyle (including routines, pets, clothing preferences, religious and cultural preferences)
- respect for property and possessions
- regular monitoring of service
- enough time for home care visits.⁽¹⁸⁹⁾

However, the study highlighted that those being interviewed sympathised with the pressures facing front-line staff and understood that practitioners too must be treated with respect and dignity.⁽¹⁸⁹⁾ From a staff point of view, if health and social care practitioners value their role and its purposes, then they will be well placed to respond with respect to the dignity of others.⁽¹⁹⁰⁾

In terms of staff training, a project in an NHS mental health trust involved people using services in collaboration with staff delivering workshops on privacy and dignity to healthcare practitioners (specifically NHS ward staff; mostly nurses and occupational therapists).⁽¹⁷⁸⁾ The study concluded that the involvement of people using services in training staff on concepts of privacy and dignity (including defining concepts, identifying best practice, discussing patient experiences, exploring improvements and developing action plans) received positive feedback from ward staff.⁽¹⁷⁸⁾ Another study showed that increasing attention to ethics in learning environments, combining ethical values and professional subjects in the curriculum, and designing training programmes based on ethics, are necessities for training managers and health and social care workers in the principle of dignity.⁽¹⁷⁷⁾ Research into training medical students to preserve patient dignity includes highlighting to medical students the value of appropriate draping of the patient during physical examination, and asking the patient for permission to enquire about sensitive

matters in their history or to conduct an uncomfortable examination.⁽¹²⁹⁾ Medical students should also be given opportunities to talk with their teachers about difficult aspects of medical care, such as dying and dignity.⁽¹²⁹⁾

5.5.7 Measuring dignity and 'patient experience'

Learning how to meaningfully measure dignity has attracted the interest of a number of policymakers and there is still work to be done in creating a set of appropriate indicators.⁽¹⁷⁶⁾ One measure would be to understand the extent to which people feel that their dignity has been maintained in health or social care services. Quality monitoring will increasingly include qualitative measures of 'patient experience', for example how patients feel staff interact with them.⁽¹⁷⁶⁾

In an Irish context, the National Patient Experience Survey 2018⁽¹⁹¹⁾ reported on patient experiences of respect and dignity while in hospital. It reported that 10,780 out of 12,858 people (84%) reported that they were always treated with respect and dignity throughout their stay. Being treated with respect and dignity was very strongly linked with patients having a positive experience overall.⁽¹⁹¹⁾

Similarly, in the UK, an analysis of human rights-related questions in the NHS inpatient survey found that patients in 'outstanding' acute NHS trusts are significantly more likely to say that they are treated with dignity and respect in hospital and that they have the emotional support that they need. Their overall satisfaction with their hospital stay was also higher.⁽⁶⁴⁾

A study in the UK determined the extent to which patients' rights to privacy and dignity were respected in the NHS when judged against seven factors of 'privacy and dignity' (outlined in the Essence of Care document). The study measured practices against the following 'benchmarks of best practice':⁽¹⁷⁹⁾

- attitudes and behaviours: patients feel that they matter all of the time
- personal world and personal identity: patients experience care in an environment that actively encompasses individual values, beliefs and personal relationships
- personal boundaries and space: patients' personal space is actively respected by all staff
- communication between staff and patients takes place in a manner that respects their individuality
- patient information: patient information is shared to enable care, with their consent

- privacy, dignity and modesty: patients' care actively promotes their privacy and dignity, and protects their modesty
- availability of an area for complete privacy: patients and carers can access an area that safely provides privacy.⁽¹⁷⁹⁾

From the perspective of a person using services, a guide developed by the Equality and Human Rights Commission in the UK sets out the standards to be expected from home care services. It explains how human rights are protected when using home care services and under the topic of dignity, it includes asking questions about home care such as:⁽¹⁹²⁾

- Am I being treated with respect?
- Am I being listened to and not ignored?
- Is there respect for my cultural heritage or religion?
- Am I being provided with adequate care as stated in my care plan?⁽¹⁹²⁾

To conclude, the concept of dignity is central to all human rights and overlaps with other principles such as privacy and respect. Violations of dignity typically relate to Articles 3 and 8 of the ECHR. Patient experience surveys are a useful way of measuring the degree to which people using services feel they were treated with dignity in a health or social care setting. While there are some resources and training guides for staff in health and social care settings about dignity, none have been developed specifically for an Irish setting.

5.6 Principle 5: Autonomy

5.6.1 Introduction

Autonomy is defined as the ability of an individual to direct how they live on a day-to-day basis according to their values, beliefs and preferences.⁽¹⁹³⁾ Autonomy is the principle of self-determination whereby a person is allowed to make free choices about what happens to them – that is, the freedom to act and the freedom to participate in decision-making based on clear, sufficient and relevant information and opportunities.⁽¹²⁾ In a health and social care setting, self-determination involves the person who uses services making informed decisions about the care, support or treatment that they receive. The ability to be autonomous, and make decisions, can be supported and developed.⁽¹⁹³⁾ The Care Quality Commission in the UK defines autonomy as the ability of a person using a service to exercise the maximum amount of choice and control possible – in care planning, in their individual care and treatment, in service development, in their relationships with others such as family and friends, and as citizens beyond the health and social care services that they are

using.⁽³²⁾ Respect for patient autonomy has been described as the core legal and ethical principle that underlies all human interactions in healthcare.⁽¹²⁷⁾

Autonomy relates to Universal Declaration of Human Rights Article 3, the right to life, liberty and security of person, and Article 12, which states that no person should be subjected to arbitrary interference with their privacy, family, home or correspondence. In the European Convention on Human Rights, Article 5 guarantees the right to liberty and security of person and Article 8 asserts a person's right to respect for their private and family life, their home and their correspondence.⁽¹¹⁾ Autonomy is also one of the four central principles of biomedical ethics.⁽¹⁹⁴⁾

This section will look at autonomy in the context of key actions and terminology used in health and social care settings. The following will be discussed:

- Informed consent and capacity
- 'Best interests' and proportionality
- Autonomy and restraint
- Putting the theory of autonomy into practice and examples of how services can start implementing an autonomy-supportive environment

Finally, this section will provide practical examples of what an autonomy-supportive approach looks like and an overview of current tensions in implementing a human rights-based approach.

5.6.2 Informed consent and capacity

In health and social care settings, autonomy is often related to a person's ability to provide informed consent.⁽¹⁹⁵⁾ Informed consent has been described as the cornerstone of patient autonomy.⁽¹²⁷⁾ Respect for autonomy means that informed consent involves a process of communicating with people, and not merely the signing of a consent form.⁽¹⁹³⁾ It is about providing a person with comprehensive information, allowing them to make independent choices.⁽¹²⁷⁾ The importance of ensuring a clear and consistent process is in place for obtaining consent has been previously discussed under the principle of fairness in section 5.2.

People have the right to obtain information about their healthcare. They have also the right to accept or reject any suggested options for care or treatment. In a hospital setting, paternalistic approaches to patient autonomy, for example making decisions 'in the best interest of the patient', can mean a patient is denied full autonomy to express their will and preferences, decisions and actions.⁽¹⁹⁵⁾

Respect for autonomy means that every adult has a right to consent to, or refuse, treatment and make decisions about their healthcare in general. However, in certain situations it may be decided that they do not have the capacity (ability) to do so.⁽¹⁹³⁾ In the UK, current legislation aimed at safeguarding the human rights of people with reduced or limited cognitive or decision-making capacity includes the Adults with Incapacity (Scotland) Act 2000, which includes guidance for decision-making on behalf of an adult who has been deemed not to have full capacity.⁽¹⁹⁶⁾ This Act enshrines in law the right of the adult to have their views and wishes, past and present, taken into account, alongside those of their nearest relative and primary carer. In England and Wales, the Mental Capacity Act 2005 enshrines a legal right to autonomy of people lacking decision-making capacity, including people with dementia.⁽⁵⁵⁾ This Act presumes that everyone has decision-making capacity until proven otherwise, and it requires that people be supported to use their remaining decision-making capacity. Ireland's 'Ward of Court' system does not clearly define 'competence' and 'capacity'.⁽¹⁹⁷⁾ However, the Assisted Decision-Making (Capacity) Act 2015,⁽⁴⁸⁾ yet to be fully commenced, presumes capacity unless a person has shown they are unable to:

- understand the information relevant to the decision
- retain that information long enough to make a voluntary choice
- use or weigh that information as part of the decision-making process
- communicate his or her decision (whether by talking, writing, using sign language, assistive technology, or any other means) or, if the implementation of the decision requires the act of a third party, to communicate by any means with that third party.

All practicable steps in assisting a person with decision-making must be taken before assessing their capacity. Moreover, in Ireland the HSE National Consent Policy notes that formal steps to assess capacity should only be considered if the person is unable to communicate a clear and consistent choice or is unable to understand and use the information and choices available to them after all appropriate help and support has been provided.⁽¹³³⁾ If a formal assessment of a person's capacity is deemed necessary, the responsibility lies with the service provider to carry out an assessment using the criteria, set out in law, to indicate if a person lacks capacity. Even if a person is deemed to lack capacity and decisions are being made on their behalf, the situation must be kept under review, acknowledging the fact that capacity can fluctuate.⁽⁶²⁾

5.6.3 'Best interests' and proportionality

The 'best interests' approach is seen as an inherently paternalistic approach that infringes on a person's right to autonomy and to fully express their will, decisions and actions.^(195,198,199) Under this approach, in the event that a person is deemed not to have capacity, the 'best interests' of the person are determined by the healthcare provider. This means a healthcare practitioner will decide what course of action would be in the best interest of the person because the person does not have capacity to decide themselves. A decision can be made in collaboration with a person's carer, family members or advocate. The Expert Group reviewing the Irish Mental Health Act recommended replacing the principle of 'best interests', with principles of:

- enjoyment of highest attainable standard of mental health
- autonomy and self-determination
- dignity
- bodily integrity
- least restrictive care.⁽¹⁹⁸⁾

Although the principle of 'best interests' is maintained in the Northern Ireland Mental Capacity Bill 2014, the law contains stronger guidelines on how to prevent it from being overly paternalistic.⁽¹⁹⁸⁾ Ireland's Assisted Decision-Making (Capacity) Act 2015 requires people supporting a person using a service to make every effort to enable them to express their 'will and preferences', but the 2015 Act does not include any reference to a 'best interests' principle.⁽²⁰⁰⁾

The principle of proportionality relates to 'best interests' when a healthcare practitioner has taken on the role of decision-maker for a person who has been assessed as lacking capacity. The healthcare practitioner should ensure that the action being taken in a person's best interest is proportionate to the situation at hand.^(128,201) This principle can be applied in order to provide the least restrictive care and to provide a service that does not infringe on the rights of a person unless it is in the 'best interests' of the person. The chosen intervention must be justifiable and strike a balance between the risk to others and the risk to a person's own wellbeing and safety.⁽²⁰¹⁾ The principle of proportionality can help to ensure the correct emphasis is placed on the most important elements of the 'best interests' situation in question.⁽²⁰¹⁾

5.6.4 Autonomy and restraint

Restraint is perhaps the most controversial issue regarding a person's right to autonomy. Restraint is a direct denial of a person's human right to liberty. Restraint[‡] can take the form of: physical restraint where a person's bodily movement is directly limited by another person; mechanical restraint when a person's movement is restricted through use of, for example, a heavy table or belt; chemical restraint which uses drugs to make a person docile or compliant; and environmental restraint which includes any electronic or physical barrier to freedom in a care setting.^(202,203)

In the UK, restraint, whether physical, mechanical, chemical or environmental, is potentially a violation of Article 3 of the Human Rights Act 1998.⁽²⁰⁴⁾ If a person is restrained on a regular basis from leaving the place where they are living, or is strapped into a chair for long periods without their consent, it would be difficult to argue that they are not being subjected to inhuman or degrading treatment. The use of restraints can indicate that a person's wishes are being overridden, and this should give rise to a careful assessment as to whether the person's human rights are being violated.⁽²⁰⁵⁾ In its guidance on the use of restraint, the Mental Welfare Commission for Scotland looks to the ECHR in placing the responsibility on healthcare practitioners to justify any use of restraint.⁽²⁰³⁾ The Royal College of Nursing also places responsibility on nurses to understand the practice and legal implications of restraint.⁽²⁰⁶⁾ The Mental Welfare Commission warns that, even where restraint is used in situations permitted by law (for example, under the Adults with Incapacity (Scotland) Act 2000 or the Mental Capacity Act 2005), if restraint is excessive, unnecessary, degrading or unnatural, the courts are likely to view this as assault and a breach of human rights; those involved could face criminal prosecution.⁽²⁰⁴⁾

Restraint is often justified by nurses on safety grounds.⁽²⁰⁴⁾ In one report highlighted in the literature, a government committee in the UK investigating the prevalence and causes of elder abuse found that chemical restraint was being employed inappropriately to manage disruptive or challenging behaviour, and 'to create care environments that were characterised by docility and compliance'.⁽²⁰²⁾ The author asserts that restraint is the result of the kind of relationship service staff have with patients regarding the way their care needs are recognised and dealt with. He maintains that using restraint indicates a failure on the part of a service to meet these needs effectively.⁽²⁰²⁾

[‡] In the Irish context, restraint comes under the definition of restrictive practices, which are practices that intentionally limit a person's movement, communication or behaviour.

5.6.5 Autonomy: Putting the theory into practice

The literature highlights that human rights policy and legislation alone do not guarantee that a human rights-based approach will be implemented in services.^(17,21,22,207,208,209) Studies carried out across Europe using the WHO QualityRights Tool Kit found that long-term institutional care for people with psychosocial and intellectual disabilities in many European countries, many of which have ratified the ECHR, is far below standard.

A significant proportion of the assessed institutions were violating the fundamental rights of people with psychosocial and intellectual disabilities, including their legal capacity, autonomy, liberty and security of person.^(17,164) Examples of a person's right to autonomy being violated included a paternalistic approach to treatment where patient empowerment was not encouraged and was actively discouraged at times. In some instances, people reported never being told what their treatment was for, and many were not consulted on their preference for treatment. Most reported not being aware of their right to appeal admission. In addition, unsafe practices around restraint were observed. De-escalation tools were not used for crisis situations; instead, police were called to restrain a person physically, verbally or as an intimidation tactic.^(17,164) In another qualitative study carried out in Norway among members of Mental Health Norway, respondents described infringements on their autonomy including incidents of involuntary commitment and forced medication and forced sterilisation, the effects of which remained with them at the time of completing the questionnaire. They also described not being listened to and being given wrong diagnoses even when they knew it was wrong.⁽¹⁴⁷⁾

5.6.6 Implementing the principle of autonomy in health and social care settings

Implementing the principle of autonomy in health and social care settings is discussed in the following sections. Firstly, the concept of relational autonomy is discussed and examples are provided. Secondly, the findings from the literature are presented on what services can do to support autonomy; this includes training staff to become more supportive of autonomy and providing autonomy-friendly workplaces.

5.6.6.1 Relational autonomy

It has been suggested that by limiting respect for autonomy to 'decision situations', a healthcare practitioner can miss the opportunity to engage with a person in looking at their healthcare situation in the context of, for example, social influences or relationships including with friends and family that may have an impact on their autonomy.^(193,195,210) Under a relational concept of autonomy, individuals are reliant

on their social experiences and relationships to influence the healthcare decisions they make.⁽¹⁹⁵⁾ Within healthcare settings, the focus shifts from the healthcare practitioner simply assessing whether a person has compromised autonomy, to involving the people who form part of a person's social network in the experience. For example, issues such as patient engagement in decision-making, confidentiality and tensions that may arise between caregivers and people using services all become relevant to the healthcare practitioner who is making decisions on behalf of the person who lacks capacity. An expanded interpretation of autonomy that includes relational autonomy would require a broader assessment and support system to help people as necessary to make decisions about their care.⁽¹⁹⁵⁾

In clinical settings, standards and common service practices could have an influence on a person's autonomy as they may feel unable to go against their healthcare providers. Illness itself can have a negative impact on autonomy by requiring changes in life plans and relationships.⁽²¹⁰⁾ Thinking of autonomy in the context of relational autonomy could mean that recommendations about treatment would be autonomy-supportive if they are made by practitioners who:

- are seeking to encourage autonomy and not just specific health gain
- listen to people using the service
- indicate to the person how they have taken into account personal circumstances, concerns and preferences in their recommendations
- empower people using the service to query and, if necessary, correct their understanding of the recommendations being made
- make sure that people using the service feel they are in a position to decide against a recommendation without putting their on-going care at risk.⁽²¹⁰⁾

5.6.6.2 What services can do to support autonomy

In order for services and health and social care practitioners to ensure that upholding a person's right to autonomy becomes an integral part of their work, the services in which they work must begin to promote a human rights-based approach in their service management plans and policies.^(22,128) It is important for services to build supportive environments for people using services which enable them to develop their capacity.⁽¹⁹⁹⁾ In its guidance document on supporting people's autonomy, HIQA highlights the fact that promoting autonomy and improving quality of life may sometimes require a degree of risk. It asserts that people who use services are entitled to the dignity and personal development associated with risk and advocates a positive approach to risk assessment which acknowledges that risk-taking forms part of a fulfilled life.⁽¹⁹³⁾

The literature also highlights the importance of health and social care practitioners understanding the power dynamic between them and the people who use services.^(17,18,210) A human rights-based approach requires the practitioner to understand the language they use in describing a person's problem and ensure that their interpretation of the problem can be understood by and is acceptable to the person using the service.⁽²¹⁰⁾ It also requires more meaningful and supportive collaboration between healthcare practitioners and people using services.⁽²¹¹⁾ It is the healthcare practitioner's responsibility to ensure they are creating an autonomy-supportive environment, but the service must also recognise and support its staff in implementing a human rights-based approach.^(22,153)

In addition to developing staff to become more autonomy-supportive and creating autonomy-friendly workplaces, the literature also highlights the importance of involving people using services in service development.⁽¹⁸³⁾ One article outlines how a group of people using services in the UK were called to be involved in service development to ensure services grew in a way that would improve the lives and prospects of those using them.⁽¹⁶⁶⁾ Another study demonstrated how collaboration between people using services and practitioners on individual risk management led to the development of trust between the two groups. This study highlighted the importance of moving towards a more inclusive, autonomy-supportive approach to risk management.⁽²¹²⁾ An evaluation of a human rights-based approach in a hospital in Scotland showed that increased collaboration between practitioners and people using services in the development of a human rights-based approach for the service led to a more positive and constructive atmosphere. It helped to build mutual respect between staff and people using services which in turn led to increased engagement between these two groups.⁽²¹³⁾

5.6.7 Supporting autonomy among people using services

The literature illustrates that a human rights-based approach to care and support can create an autonomy-supportive environment for people using health and social care services. In its booklet, *Shining a Light on Learning Disability and Human Rights: A practitioner's guide*, the British Institute of Human Rights provides a flow chart on decision-making using a human rights-based approach.⁽⁶²⁾ An NHS trust service in the UK demonstrates their risk assessment and management plan which takes a human rights-based approach by looking at risk through a 'human rights lens', identifying relevant issues and maximising the participation of people using services.⁽¹²⁸⁾ This service uses the principle of proportionality to engage in proactive rather than reactive strategies. The aim of a proactive strategy, such as providing a person with psychological therapy to help them understand why they are angry and upset after one of their parents has died, is to avoid the need for restraint (a

reactive strategy). Proactive strategies can create autonomy-supportive care environments.

In England, the Care Quality Commission uses a human rights-based approach to monitoring services, which includes:⁽³²⁾

- putting people who use services at the heart of their work
- ensuring staff who are not human rights specialists can use the human rights approach
- providing tailored advice and support within their service, from human rights specialists if required.

They provide a toolkit to assess if a service is delivering a human rights-based approach to care and support. Under autonomy, this includes the empowerment of people using services, the minimal use of restrictive practices (including restraint) through person-centred approaches, the maximisation of independence and the provision of support to help maintain friendships and relationships.⁽³²⁾

A paper from the Centre for Welfare Reform in Scotland strongly endorses the use of the FAIR model, which involves four steps of decision-making based in human rights:⁽²¹⁴⁾

- facts (gathering of facts relating to the decision)
- analysis of rights at stake
- identification of responsibilities
- review of actions.⁽²¹⁴⁾

It is used to assist social care workers to involve people who use services and families in their decision-making and deliver more personalised services, thereby helping to balance the power dynamic between services and people using services.⁽²¹⁴⁾

Using the UN Convention on the Rights of People with Disabilities⁽⁴⁶⁾ as a reference, the HSE has developed a guide for HSE Managers and Social Care staff to working collaboratively in the area of decision-making for people with disabilities that includes:⁽²¹⁵⁾

- recognising the range of disabling barriers that exist for people with a disability

- understanding of the liberating and empowering principles of the social model of disability^{*****}
- the ability to identify and challenge traditional working methods based on the medical model of disability⁺⁺⁺⁺⁺⁺⁺
- the capacity to be flexible and accommodating based on the social model of disability, which means being able to think outside the box when one size does not fit all
- recognising that effective participation requires commitment to supporting change in a meaningful way.⁽²¹⁵⁾

5.6.8 Tensions in implementing a human rights-based approach

In some instances, tensions between human rights principles can arise when a human rights-based approach is introduced. For example, a person's autonomy can appear to be in conflict with their dignity if they are admitted on an involuntary basis with a diagnosis of self-neglect secondary to psychosis.⁽¹⁸⁷⁾ Protecting a vulnerable person by restricting their right to liberty and autonomy could be seen as meeting one of the goals of legislation on human rights, however, such a decision can have distressing consequences for the person concerned even if they make a full recovery.⁽²²⁾ It might be difficult to always avoid these kinds of conflicts. However, the emphasis in a human rights-based approach to upholding a person's autonomy is to try all non-restrictive options before considering the need for involuntary treatment.^(127,187,199)

In conclusion, autonomy relates to a person's right to self-determination. In health and social care settings, this is often connected with a person's ability to provide informed consent. Informed consent must include open and clear communication with a person using services to ensure they are given complete information on their care options and are supported to make independent choices. When a person is deemed not to have the capacity to make decisions relating to their care, any intervention decided on by a health or social care practitioner must be justifiable and proportionate, weighing the risk to others and the risk to a person's own wellbeing and safety. Capacity must be continuously reviewed as it can fluctuate. One of the most serious violations of a person's autonomy can occur when restraint or

***** The social model of disability is a way of viewing the world, developed by disabled people. The model says that people are disabled by barriers in society, not by their impairment or difference.

+++++++ The medical model of disability says people are disabled by their impairments or differences. Under the medical model, these impairments or differences should be 'fixed' or changed by medical and other treatments, even when the impairment or difference does not cause pain or illness.

restrictive practices are used unnecessarily or without due consideration for proportionality. Various models and toolkits have been developed which can be used to help assess and promote autonomy in health and social care settings.

5.7 Summary of evidence synthesis

The project team carried out an evidence synthesis to retrieve and document evidence (from both grey and black literature) in relation to a human rights-based approach to health and social care for adults in Europe. The literature search and screening process took place between August and November 2018. The results were documented according to the five FREDA principles and subsequently by sub-themes, as outlined in previous sections.

Results from the evidence synthesis found more evidence available for the principles of equality, dignity and autonomy. Less evidence was available in relation to fairness and respect. Additional input will be sought from the project Advisory Group and other stakeholders, including focus group participants, for these principles.

The evidence synthesis indicated that placing people who use services at the centre of service development is a key part of a human rights-based approach. Services must ensure that people using services are communicated with appropriately, that they are fully aware of all their options regarding their care and that they are supported to exercise autonomy in decisions relating to their care and support. The literature indicates that although human rights are enshrined in law and policy documents in various jurisdictions, in practice they are not necessarily fully understood by practitioners delivering health and social care services.

A paternalistic approach to care still prevails in some services. The evidence suggests that to fully embed a human rights-based approach in health and social care services, it is necessary to educate, train and support staff in this area. The literature also highlights the importance of involving people who use services in the development of programmes and models of care that promote a human rights-based approach. Some institutions, organisations and services have already developed programmes and models that advocate patient empowerment and participation. These provide useful examples for the development of guidance on a human rights-based approach to care and support in health and social care settings in Ireland.

6. Summary, conclusion and next steps

This background document outlines the evidence that was reviewed by the project team to inform the development of guidance on a human rights-based approach to care and support in health and social care settings in Ireland.

This included:

- an overview of human rights-based approaches to health and social care services
- an overview of relevant international and Irish legislation
- an evidence synthesis of national and international literature relating to human rights-based care and support described under the FREDA principles of Fairness, Respect, Equality, Dignity and Autonomy.

Information and findings from this review will be used to inform the development of guidance to support a human rights-based approach in health and social care services in Ireland.

Key findings from the review include:

- Central to a human-rights based approach to care and support is ensuring that people who use services are placed at the heart of service development and provision. The findings from the evidence synthesis and international review indicated that a paternalistic approach to care still exists. However, services are moving away from such an approach towards a person-centred approach that promotes the empowerment and participation of people who use services in their own care, support and treatment plans. Empowerment can be fostered by clear and appropriate communication between service providers and people using services.
- Findings from the international review in particular indicated the importance of human rights being embedded in legislation and policy at central and local government level. Work in this area in Scotland and the Netherlands illustrated the benefit of creating a National Action Plan on human rights in order to progress a human rights agenda. It is important to ensure politicians and policymakers have a clear knowledge of human rights and the application of human rights in terms of both policy development and in delivering health and social care services.
- Additionally, findings from the international review emphasised the important role that human rights organisations can play in the development of

resources, tools, training and engagement to help services understand and implement a human rights-based approach in their work. Partnering with health and social care services, as demonstrated in particular by the work of the British Institute of Human Rights, in developing these resources can help to increase their relevance and accessibility to front-line staff.

- Communication is an integral part of working with people using services. The findings from the evidence synthesis highlighted the importance of providing people with adequate and accessible information on their health or personal status, to ensure they are fully aware of all their options regarding their care and support. It also highlighted the importance of ensuring that any disclosure of personal information about a person's health or personal status respects their right to a private life.
- Findings from the evidence emphasised the importance of ensuring access to appropriate health and social care services according to a person's needs. They also indicated the need for people using services to receive access to standard treatments on an equal basis with the general population.
- The evidence also underlined the importance of supporting people to exercise autonomy in decisions relating to their care and support. In addition, the findings showed the importance of decision-making processes based on the human rights of the person using services. By applying a human rights-based approach to decision-making, health and social care practitioners can weigh up the rights of the person using a service while taking into account the risks which could affect the person's or other people's safety or wellbeing.
- The findings from the evidence showed that clear processes are necessary in a service to ensure fair and consistent decision-making about care, support and treatment. This relates to the process of informed consent and ensures that the person using the service is fully informed and actively involved in the process. Each service must ensure that it has such a process in place.
- The importance of presuming an individual's capacity unless specific criteria are met is highlighted in literature. When a person is deemed not to have the capacity to make decisions regarding their care and support, any intervention decided on by a health or social care practitioner must be justifiable and proportionate, weighing up the risk to others and the risk to the person's own wellbeing and safety. Capacity must be continuously reviewed as it can fluctuate.
- The evidence demonstrated the importance of exploring options other than restraint or restrictive practices when a person using a service displays

disruptive or challenging behaviour. This includes ensuring that, if used, restrictive practices are proportionate to the behaviour they are being used to restrict; are the least restrictive; applied for the shortest possible time; and subject to a timely review.

- The findings underlined the need for human rights to be embedded in service provision rather than being seen as a separate concern. They also highlighted the importance of services developing policies and models of care and support that have human rights at their core to ensure an organisation-wide approach to implementation. Such policies and models of care can also help to prevent violations of human rights in services. Evident from the evidence synthesis was a lack of knowledge within services of what constitutes a human rights-based approach. It is necessary to educate, train and support staff on how to embed this approach in their everyday work. It is also important to involve people using services in the development of services.
- Also emphasised was the need for health and social care providers to understand the barriers facing people using services and to make sure that they directly engage with people to understand their needs and views. This means acknowledging and accommodating difference rather than treating everyone the same. It is about recognising that, although everyone has the same human rights, different groups may have additional needs. It is important for services to provide additional supports for these groups to ensure their needs are met.
- The international review also highlighted the importance of developing indicators to monitor human rights. At a local level this included the development of human rights and equality impact assessment tools for organisations to reflect on their service provision in relation to human rights.

This document will inform an initial draft of the guidance in conjunction with:

- detailed discussions at meetings of the project Advisory Group
- individual meetings with relevant informed and interested parties
- focus groups with:
 - people who use health and social care services
 - front-line staff and management in these services
 - relevant advocacy groups.

When the draft guidance is developed, a public consultation will be held. Submissions received during this consultation will be reviewed and carefully considered, and the guidance may be revised and improved based on the feedback received. The main amendments will be published in a related statement of outcomes document along with the final guidance which will be available on HIQA's website.

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Appendix 1 – The relationship between the National Standards developed by HIQA and the specific human rights as set out in the European Convention on Human Rights

Human Rights	<i>National Standards for Safer Better Healthcare (2012)</i>	<i>National Standards for Residential Services for Children and Adults with Disabilities (2013)</i>	<i>National Standards for Residential Care Settings for Older People in Ireland (2016)</i>	<i>National Standards for Safer Better Maternity Standards (2016)</i>
Article 3. The right to freedom from torture and inhuman or degrading treatment	'Service providers ensure all reasonable measures are taken to protect service users from abuse.' (Standards 3.4)	'Each person is protected from abuse and neglect and their safety and welfare is promoted.' (Standard 3.1)	'Each resident is safeguarded from abuse and neglect and their safety and welfare is promoted.' (Standard 3.1)	'Maternity service providers ensure all reasonable measures are taken to protect women and their babies from all types of abuse.' (Standard 3.7)
Article 5. The right to liberty and security	-	'People living in the residential service are not subjected to a restrictive procedure unless there is evidence that it has been assessed as being required due to a serious risk to their safety and welfare.' (Standard 3.3)	'Arrangements to protect residents from harm promote bodily integrity, personal liberty and a restraint-free environment in accordance with national policy.' (Standard 3.5)	-

<p>Article 6. The right to a fair trial*</p> <p>* In the context of health and social care settings this goes beyond the process of a legal trial and includes decision-making processes, for example making a complaint, making a compensation claim, commencing staff disciplinary proceedings or tribunals in health and social care settings.</p>	<p>'Clear and transparent decision-making processes, including referral pathways, to facilitate service users' access to healthcare services. The effectiveness of these processes is regularly evaluated.' (Feature 3 of Standard 1.2)</p>	<p>'The residential service demonstrates transparent and effective decision making when planning, procuring and managing the use of resources.' (Feature 4 of Standard 6.1)</p>	<p>'The residential service demonstrates transparent and effective decision-making when planning, procuring and managing the use of resources.' (Standard 6.1.4)</p>	<p>'Governance arrangements are in place to ensure the interests of women and babies using the service are taken into consideration when decisions are made about the planning, design and delivery of services, such as including former patients and service users in these processes, for example, through a maternity service liaison committee.' (Feature 4 of Standard 5.2)</p>
<p>Article 8. The right to respect for private and family life</p>	<p>'Service users' dignity, privacy and autonomy are respected and promoted.' (Standard 1.6)</p> <p>'Service providers promote a culture of kindness, consideration and respect.' (Standard 1.7)</p> <p>'Service users are supported in maintaining and improving their own health and wellbeing.' (Standard 1.9)</p>	<p>'The privacy and dignity of each person are respected.' (Standard 1.2)</p> <p>'Each person develops and maintains personal relationships and links with the community in accordance with their wishes.' (Standard 1.4)</p> <p>'The residential service is homely and accessible and promotes the privacy, dignity and safety of each person.' (Standard 2.2)</p>	<p>'The privacy and dignity of each resident are respected.' (Standard 2.2)</p> <p>'Each resident develops and maintains personal relationships and links with the community in accordance with their wishes.' (Standard 1.4)</p> <p>'Each resident continues to receive care at the end of their life which respects their dignity and autonomy and meets their physical, emotional, social and spiritual needs.' (Standard 2.5)</p>	<p>'Women and their babies experience maternity care which respects their diversity and protects their rights.' (Standard 1.3)</p> <p>'The dignity, privacy and autonomy of each woman and baby is respected and promoted.' (Standard 1.6)</p> <p>'Maternity service providers promote a culture of caring, kindness, compassion, consideration and respect' (Standard 1.7)</p>

			'The residential service is homely and accessible and provides adequate physical space to meet each resident's assessed needs' (Standard 2.6)	
Article 9. Freedom of thought, conscience and religion	'Facilitation of service users to exercise civil, political and religious rights as enshrined in Irish law, as far as is reasonably practicable, when they are receiving healthcare.' (Feature 1 of Standard 1.3)	'Each person exercises choice and experiences care and support in everyday life.' (Standard 1.3)	'Each resident has a right to exercise choice and to have their needs and preferences taken into account in the planning, design and delivery of services.' (Standard 1.3)	'Services are flexible, accessible and culturally sensitive and planned individually to motivate all women — including vulnerable and marginalised women — to engage with services.' (Feature 3 of Standard 1.3)
Article 10. Freedom of expression	'Service users are enabled to participate in making informed decisions about their care.' (Standard 1.4) 'Service users' informed consent to care and treatment is obtained in accordance with legislation and best available evidence.' (Standard 1.5)	'Each person makes decisions and has access to an advocate and consent is obtained in accordance with legislation and current best practice guidelines.' (Standard 1.6)	'Each resident, where appropriate, is facilitated to make informed decisions, has access to an advocate and their consent is obtained in accordance with legislation and current evidence-based guidelines.' (Standard 1.6)	'Women are empowered to make informed decisions about their care.' (Standard 1.4)

Article 13. Right to an effective remedy	'Service users' complaints and concerns are responded to promptly, openly and effectively with clear communication and support provided throughout this process.' (Standard 1.8)	'Each person's complaints and concerns are listened to and acted upon in a timely, supportive and effective manner.' (Standard 1.7)	'Each resident's complaints and concerns are listened to and acted upon in a timely, supportive and effective manner.' (Standard 1.7)	'Women or families who make a complaint are helped with accessing support services, such as independent advocacy services.' (Feature 5 of Standard 1.9)
Article 14. Freedom from discrimination	'Initial and ongoing access to healthcare for service users which is in compliance with legislation and does not discriminate according to age, gender, sexual orientation, disability, marital status, family status, race, religious belief, or membership of the Traveller Community.' (Feature 2 of Standard 1.3)	'Social, religious and cultural beliefs and values are respected and valued in the everyday activities of the residential service.' (Feature 6 of Standard 1.3)	'Each resident is treated with dignity, respect and kindness. Their equality is promoted and respected in relation to the resident's age, gender, sexual orientation, disability, family status, civil status, race, religious beliefs and membership of an ethnic group or Traveller community.' (Feature 3 of Standard 1.1)	'Initial and ongoing access to maternity care complies with legislation and does not discriminate according to age, gender, sexual orientation, disability, civil status, family status, race, religious belief, or membership of the Traveller Community.' (Feature 1 of Standard 1.3)

Appendix 2 – International stakeholders

Country	Name	Organisation	Role
England	Lucy Wilkinson	Care Quality Commission	Equality, Diversity and Human Rights Manager
	Margaret Flaws	Care Quality Commission	Senior Equality, Diversity and Human Rights Officer
	Sanchita Hosali	The British Institute of Human Rights	Director
	George Sullivan	Mersey Care NHS (re. community and mental health) Foundation Trust	Equality and Human Rights Advisor for Secure Services/ Registered Nurse in Mental Health
Scotland	Fiona Wardell	Healthcare Improvement Scotland	Standards and Indicators Lead
	Cathy Asante	Scottish Human Rights Commission	Legal Officer – Human Rights Based Approach
Iceland	Margrét Steinarsdottir	Icelandic Human Rights Centre	Director
	Hrefna Thengilsdottir MD	Directorate of Health	Senior Medical Officer
Netherlands	Ineke Boerefijn	Netherlands Institute for Human Rights	Coordinating Policy Advisor
	Jonneke Naber	Netherlands Institute for Human Rights	Policy Advisor
	Hans Rohlof	Johannes Wier Stichting	Board Secretary



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Safeguarding
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Promoting the rights of vulnerable adults