

Statement of outcomes report on public engagement on draft Guidance on a Human Rights- based Approach in Health and Social Care Services

November 2019



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 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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Chapter 1 Introduction and background

The Health Information and Quality Authority (HIQA) has developed *Guidance on a Human Rights-based Approach in Health and Social Care Services*. This guidance was developed in conjunction with Safeguarding Ireland and was part-funded by the Irish Human Rights and Equality Commission.

While existing national standards¹ make high-level reference to a human rights-based approach to care and support, a dedicated guidance document will aim to focus attention on a human rights-based approach by:

- offering a common language and framework to describe a human rights-based approach to care and support in health and social care services for adults
- supporting health and social care practitioners' understanding of human rights and the important elements of a human rights-based approach to care and support
- promoting effective and up-to-date practices that reflect best practice in terms of a human rights-based approach
- helping staff to incorporate human rights legislative requirements into their practice and to embed a human rights culture within their organisations
- assisting staff to implement aspects of national standards which focus on a human rights-based approach to care and support
- enabling a person-centred approach by focusing on the legally protected rights of people using health and social care services
- helping people who use health and social care services to understand what they should expect from a service committed to respecting, protecting and promoting their human rights.

People using health and social care services in Ireland should expect that their human rights will be promoted and protected during those times when they require the care and support of health and social care services. A human rights-based approach to care and support is about people using services being treated with fairness, respect, dignity and equality, and being supported to have a say over their

¹ Respect for human rights is implicit within national standards, for example *National Standards for Safer Better Healthcare* (2012) as well as other national standards developed by HIQA in the areas of older persons, disability, maternity, and adult safeguarding.

lives and participate as fully as possible in decisions around their care and support. A human rights-based approach is thus integral to people's experience of care and support, as well as their outcomes. It is expected that all health and social care services will adopt a human rights-based approach to protect the human rights of people using services, and to support positive experiences of care and support, in addition to best possible outcomes from care and support, for everyone.

A focused review was undertaken to inform the development of the guidance. It summarised international, national and academic evidence on a human rights-based approach to care and support through international standards, guidelines and support tools, national and international legislation and policy, and peer-reviewed academic publications. All of the documents that were reviewed and assessed to inform this guidance are outlined in the *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), available at www.hiqa.ie.

Stakeholder engagement is a key component of the guidance development process. While the research undertaken ensures that the guidance is evidence-based, engagement with stakeholders ensures that the guidance is appropriate to the Irish context, will improve the experience of people using services and can be implemented in practice. The different methods of engagement, as outlined in this document, also provide an opportunity to raise awareness of the importance of the guidance and to ensure buy-in from relevant stakeholders.

An Advisory Group, comprised of a diverse range of interested and informed parties, including representatives from advocacy groups, health and social care professionals, and statutory bodies, including the Irish Human Rights and Equality Commission, was convened to advise on the development of *Guidance on a Human Rights-based Approach in Health and Social Care Services*. Two meetings of the Advisory Group were held. The first meeting of the group took place on 30 January 2019 to discuss the findings from the initial stakeholder engagement and the background document to inform the guidance. The second meeting of the group took place on 21 August 2019 to discuss changes to the guidance resulting from the public consultation. HIQA gratefully acknowledges the hard work and commitment of the Advisory Group. The members of this group are listed in Appendix A of this report.

This Statement of Outcomes report outlines the process and outcome of the following consultation stages of the guidance development:

Scoping consultation	October 2018	51 responses
Focus groups	January 2019	6 groups, 39 participants
	June 2019	3 groups, 20 participants
Public consultation	June – July 2019	75 responses

Chapter 2 Overview of the process

2.1 Overview of the scoping consultation process

To promote engagement and participation by informed and interested parties in the development of the guidance, HIQA held two public consultations. The first consultation, held at the beginning of the guidance development, was a scoping consultation asking people with experience of health and social care services (including people using services, staff, advocates and family members) and the public for their views on the key areas that the guidance should address. This consultation also asked for opinions on the key sources of information and evidence the Project Team should review, and the key organisations or individuals the team should engage with, in the development of the guidance.

The scoping consultation ran for four weeks from 3 October 2018 to 31 October 2018. A consultation form (see Appendix B) was developed to assist people to make submissions. Submissions could be made using an online survey tool, emailed to a dedicated email address or posted to HIQA.

In total, 51 responses were received. All submissions to the scoping consultation were considered and informed the areas covered by the guidance, as well as the evidence review and stakeholder engagement plan for the guidance development. See Appendix C for list of organisations that made submissions to the scoping consultation.

2.2 Overview of how focus groups that informed the development of the guidance were conducted

When developing guidance, experts, service providers, people using services, the general public and other key stakeholders are consulted. Focus groups are one way of consulting and engaging with these stakeholders.

During the development of this guidance, the Project Team conducted nine focus groups in Dublin and Cork. These groups discussed their experience of health and social care services and their opinions on what issues the guidance should address. People who attended these focus groups included:

- front-line staff
- service managers
- advocates
- people using services.

There was representation from a range of health and social care services across the focus groups, including disability, older persons, mental health, and acute and primary care services; and staff disciplines included social work, nursing, general practice, addiction, physiotherapy, speech and language therapy, occupational therapy and psychology. Focus group participants were identified through the scoping consultation. As part of the scoping consultation, respondents were asked if they would like to be involved in future focus groups relating to the development of the guidance. Respondents who expressed interest in this were subsequently contacted and invited to participate. Where it was noted that there was a lack of representation from key groups, nominations were sought through contacts in relevant services and organisations.

Six focus groups were held with 39 participants for scoping purposes and took place prior to the public consultation to determine what the guidance should include. The remaining three focus groups were held with 20 participants for review purposes and took place during the public consultation to seek feedback on the draft guidance.

A briefing document was sent to all participants in advance of the focus groups. This outlined the purpose of the focus groups, key questions for consideration and how the groups would be conducted. The schedule of questions used in the focus group discussions can be found in Appendix D.

At least two members of HIQA's Project Team attended each focus group; one facilitated the group and the other(s) acted as note taker(s). It was explained in each session that the notes taken would only be used to inform the development of the guidance and points would not be attributed to any individual. All of the feedback gathered at the focus groups was reviewed and considered by the Project Team and incorporated into the development of the guidance.

2.3 Overview of the public consultation process

A second consultation was held when HIQA published the *Draft Guidance on a Human Rights-Based Approach to Care and Support in Health and Social Care Settings* for a six-week public consultation from 5 June 2019 to 17 July 2019. The purpose of this consultation was to gather feedback on the content and structure of the draft guidance. A draft guidance document was made publicly available to download on www.hiqa.ie.

A consultation form (see Appendix E) was developed to assist people to make submissions. Submissions could be made using an online survey tool, emailed to a dedicated email address or posted to HIQA.

At the start of the second public consultation, the Project Team notified members of the Advisory Group about the consultation process and asked that they notify the groups they represent and other interested colleagues. The Project Team also contacted focus group participants, relevant health and social care professionals, advocacy groups and interested stakeholders by email to inform them of the process and request that they share information about the public consultation and encourage their colleagues to participate in the process. In order to reach as wide a range of stakeholders as possible, the public consultation was advertised in HIQA's newsletter and on its website. In addition, a press release about the public consultation was issued, and the consultation was advertised periodically via HIQA's social media channels, including Twitter, LinkedIn and Facebook.

A total of 75 responses were received in relation to the draft guidance. All submissions to the second consultation were considered and the *Guidance on a Human Rights-based Approach in Health and Social Care Services* was revised accordingly. See Appendix F for list of organisations that made submissions to the public consultation.

This statement of outcomes report gives an overview of the feedback received during the focus groups and submissions received during the public consultations, as well as HIQA's response to those submissions.

HIQA is very grateful to those who participated in the focus groups and those who made submissions to the public consultations for taking the time to contribute to the development of the guidance.

Chapter 3 Analysis of the scoping consultation

This chapter presents an overview of the analysis of the responses received during the scoping consultation and how HIQA used this information to inform the development of the guidance.

3.1 Overview of scoping consultation submissions

There were 51 responses received over the initial four-week scoping consultation phase. In the 'About you' section, respondents were asked if they were commenting on behalf of an organisation or in a personal capacity. If they were making the submission on behalf of an organisation, they were asked to include the name of the organisation. Respondents were also asked whether they were commenting as a person who has used health and social care services or as a staff member or other person working in a health and social care service. Respondents who worked in a health or social care service were asked to specify their role. Respondents making a submission on behalf of an organisation were asked to provide contact details so that these submissions could be verified.

The consultation comprised three general questions asking what key areas the guidance should address, the key sources of information the Project Team should review, and the key organisations or individuals the team should engage with in the development of the guidance. This statement of outcomes document provides an overview of the submissions received for each question.

3.2 Results of the scoping consultation submissions

Of the 51 responses, 22 people (43%) responded in a personal capacity and 29 people (57%) responded on behalf of an organisation. Of the 51 respondents:

- 25 (49%) stated that they were providing feedback as a staff member or other person working in a health and social care service
- 24 (47%) stated they were commenting as a person who has used or is currently using health and social care services and
- two (4%) stated they were commenting in an 'other' capacity.

Forty-seven respondents (92%) gave details of their roles. Examples of the roles of respondents working in health and social care services include:

- Carer
- Director of nursing

- Health policy officer
- Pharmacist
- Physiotherapist
- Public health nurse
- Social care worker
- Social worker
- Speech and language therapist
- Quality and compliance manager.

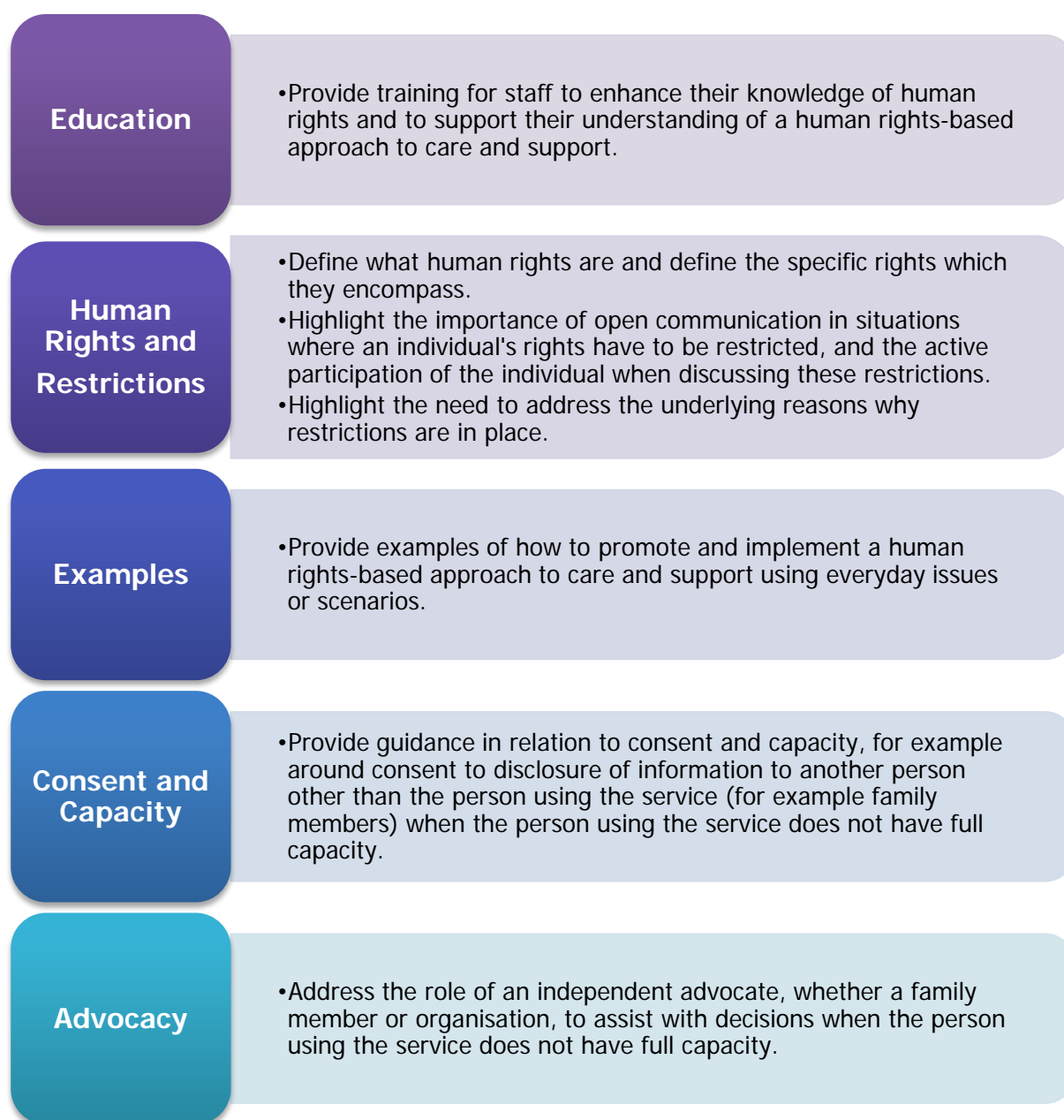
See Appendix C for examples of the types of organisations that made submissions to the scoping consultation.

3.3 Key areas the guidance should address

This question asked respondents 'What are the key areas that the guidance should address?'. All respondents answered this question. The key areas identified by respondents were reviewed by the Project Team and categorised into five themes. Figure 1 summarises the key areas identified by respondents under the five themes.

The key areas identified by respondents were presented to the Advisory Group at its' first meeting on 30 January 2019. Together with the feedback received from the scoping focus groups and the review of the evidence base, these key areas were considered by the Project Team in defining the scope and content of the guidance.

Figure 1. Responses to consultation question regarding key areas the guidance should address



3.4 Key sources of information to inform the guidance

This question asked respondents 'What are the key sources of information that should be reviewed to inform the development of the guidance?'. Fifty respondents (98%) answered this question. Over 300 sources of information were suggested, including legislation, policies, standards and guides, books, journal articles, and websites. All information sources suggested by respondents were compared with the sources already identified by the Project Team through HIQA's evidence synthesis

process; and any new relevant sources were added to the evidence base to inform the development of the guidance.

3.5 Key organisations or individuals to engage in guidance development

This question asked respondents what key organisations or individuals the Project Team should engage with when developing the guidance. Forty-nine respondents (96%) answered this question. While there were many organisations and individuals suggested, the most frequent suggestions were:

- Age Action
- Disability Federation of Ireland
- HSE – this included specific groups within the HSE, for example the Mental Health Engagement Office
- Inclusion Ireland
- National Federation of Voluntary Bodies
- People who use health and social care services
- SAGE.

The Project Team conducted a comparison between the organisations and individuals suggested by respondents and the stakeholders included in the stakeholder engagement plan for developing the guidance. Where it was noted that there was a lack of representation from key groups or organisations, these were added to the stakeholder engagement plan.

3.6 Future engagement

Respondents were asked if they would like to hear about opportunities to engage with HIQA in the future on the development of this guidance (for example, to participate in focus groups). The majority of respondents (90%, or 45 people) stated that they would like to be contacted in future. All interested respondents were subsequently contacted and invited to participate in focus groups to inform the development of the guidance.

Chapter 4 Analysis of focus group discussions

4.1 Feedback from scoping focus groups (pre-public consultation)

The Project Team analysed all of the feedback received from the focus groups and collated it under the five principles within the FREDA framework. The FREDA framework is the organising framework through which the *Guidance on a Human Rights-based Approach in Health and Social Care Services* is presented. It is an internationally recognised framework through which human rights can be considered and consists of the following five principles: Fairness, Respect, Equality, Dignity, and Autonomy.

The findings from the scoping focus groups were presented to the Advisory Group at its' first meeting on 30 January 2019. Together with the feedback received from the scoping consultation and the review of the evidence base, these findings were considered by the Project Team in defining the scope and content of the guidance.

The findings from the focus groups are outlined below under each of the FREDA principles. Additional points raised that did not fall under the FREDA principles were also identified and are included in this chapter.

Theme 1: Fairness

Fairness means ensuring that when a decision is made with a person using a service about their care and support, that the person is at the centre of the decision-making process.

Participants discussed the lack of awareness among people using services and their families in the area of a human rights-based approach to care and support. It was emphasised that people using services and their families need to be empowered and facilitated, through education and awareness-raising exercises, to claim their rights and to know what to expect from a service. Participants highlighted that service providers and staff at all levels also require information and training to protect human rights, to educate and empower people using services, and to ensure full implementation of a human rights-based approach across all services.

Focus group participants emphasised the importance of people using health and social care services being given a choice on how they would like to receive information. They noted that information must be provided in a way that is accessible to people and discussed potential challenges in providing accessible information to people with intellectual disabilities and people with communication difficulties.

Participants discussed the importance of good communication when providing information to people using services about their health status, diagnosis and treatment. They noted the importance of providing information on all treatment options to the person using the service, including information on the risks associated with each option. It was noted by participants that the treatment options discussed should include options that the service itself cannot provide.

Participants discussed the importance of patient consent. They noted that obtaining full consent was time and resource intensive, but ultimately a worthwhile process. Obtaining consent in an acute healthcare setting was described by one participant as often a rushed exercise where the main objective is to get a signature from the person to consent to the treatment or intervention. The need for better tools and guidance around consent for adults with intellectual disabilities was also highlighted.

The importance of respecting a person's wishes regarding who can view their medical information was discussed by participants. They noted the importance of appropriately balancing the need to share information for the benefit of the person using the service with the need to protect the person's right to privacy. Participants noted that while respect for privacy has improved in primary care, a culture remains within hospitals where respect for privacy is not always prioritised.

Focus group participants highlighted that lack of awareness of human rights can lead to inappropriate use of restrictive practices. Participants explained that in disability services, blanket policies often exist without any awareness of how they may infringe on the human rights of people using services. Participants pointed to the importance of providing individualised care and support for people using services.

Participants discussed the need for service planning and evaluation, and the development of processes, procedures and policies within services, to take a human rights-based approach to care. The potential benefits of establishing a human rights committee were discussed. In addition, participants felt that training and education was needed to change the culture of an organisation.

Supporting autonomous decision-making was viewed by participants as central to a human rights-based approach to care and support. Participants stated that it was important that decisions are made 'with' and not 'for' people using health and social care services. This approach should be evident in the everyday decisions that people using services make, for example about what they eat, wear, and who they have relationships with. Participants noted that supporting people's autonomy and meaningful participation during decision-making can affect care positively. They emphasised that people using services have the right to decide to refuse a service and also have the right to refuse to take part in shared decision-making if they wish.

Theme 2: Respect

Respect is the objective, unbiased consideration and regard for the rights, values, beliefs and property of other people.

Participants discussed the need to respect a person's right to make a choice. They emphasised the importance of taking the time to explain a care plan or treatment options clearly and to discuss the wishes or needs of the person. Participants noted that asking what a person's wishes are is often met with fear of not being able to deliver what the person requests. Nevertheless, the group noted that it is still important to have the conversation and to be open.

Communication was viewed as core to a person's ability to express their rights. Participants noted that it is essential that staff have the time and skill to use a range of methods to understand what the person is trying to express. A useful question was provided: 'What is the person trying to communicate through their behaviour?'

Participants reported that facilitating relationships and discussing sexuality is often avoided in care settings because it is seen as a difficult topic area to address. It was felt that there are inconsistent attitudes among practitioners, particularly in relation to people with intellectual disabilities, and that many settings lack processes and procedures around communicating and facilitating a person's wishes regarding sexuality and relationships.

Theme 3: Equality

Equality means people having equal opportunities and being treated no less favourably than other people on the grounds set out in legislation.

Focus group participants noted that for people not using services, day-to-day rights are upheld without having to be stated, and that this should be the same for people using a service. It was suggested that it would be useful to ask staff to think about all the decisions that they have made in the past three hours and then think about what it would be like if someone else was making these decisions for them.

Participants emphasised the importance of health and social care practitioners keeping in mind the social determinants of health.² They noted that services must always see 'people as people' regardless of their background while also acknowledging and accommodating the diverse needs of people using services and

² The social determinants of health are the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life. These forces and systems include economic policies and systems, development agendas, social norms, social policies and political systems.

not treating everyone the same. Participants highlighted that people who are non-verbal should be treated as having the same capacity as others; each stage of care should be explained to them and support provided, using appropriate methods and tools, to enable them to express their wishes for their care.

Participants discussed how a human rights-based approach includes a person being enabled to achieve their role in society. They felt it was vital that a person using a service is facilitated to achieve a quality of life that is meaningful to them as an individual.

Theme 4: Dignity

Dignity means treating people 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.

Focus group participants drew attention to the tendency for people using services to in effect 'hand over' their rights to the healthcare providers in a medical setting. They pointed to examples of dignity being infringed upon in different health and social care settings, including people using mental health services receiving injections in front of other patients or visitors; people in drug treatment services being requested to urinate in front of others; and the lack of privacy in an emergency department during a distressing episode.

Participants emphasised that the dignity and personal integrity of people using services should be respected at all times. They noted that a human rights-based approach must ensure that a respectful relationship is maintained between the practitioner and the person using the service, for example older people should not be treated like children. Participants highlighted the importance of staff who are friendly, supportive and open. They noted how a good relationship with staff can help people using services through difficult times.

Theme 5: Autonomy

Autonomy is the ability of a person to direct how they live on a day-to-day basis according to personal values, beliefs and preferences.

Focus group participants highlighted the importance of staff working in partnership with people who know the person using the service well, and with experts, to support the person to articulate how they want their rights to be implemented in practice. Participants discussed the difficulties that staff can experience when working with family members and the parents of people over 18 years, who feel they have control over the care of the person accessing the service. Participants

noted that while it is important to respect the views of family members, the person using the service should be at the centre of the decision-making process and must have the final decision.

Participants emphasised that people using services need to be supported to have control in their own lives. They noted that services can be risk averse, in order to protect themselves and act based on 'best interests' rather than in line with the person's will and preferences. They highlighted that positive risk-taking may put staff in a difficult position as they may be in breach of a service policy or system. They noted it can also be difficult for staff to stand by while the person using the service makes 'bad' decisions. They felt that there was fear among staff around being responsible for a bad outcome. Nonetheless, participants noted it is the role of the staff member to ensure the person's long-term needs are met by engaging in person-centred planning and addressing any violations of a person's rights. They discussed the need for staff to be supported around positive risk-taking, particularly if an outcome is not positive.

Focus group participants drew attention to the need to recognise that a person's capacity to make a decision can fluctuate and a person who may not be able to make a decision about a particular matter today may have capacity to make that decision in the near future.

Participants felt that professional patient advocates should be available to anyone and that people using services should also be supported to build the capacity to advocate for themselves.

Theme 6: Additional points raised

Focus group participants discussed the challenges in applying a human rights-based approach to care, including a lack of resources, a lack of buy-in from staff and management, high staff turnover in certain services, and the reliance on agency staff who have limited knowledge of the person. Implementing a human rights-based approach was felt by participants to come down to attitudes. Participants suggested that in order to achieve buy-in and a shift in attitude within services, there has to be a top-down mandate, the terminology of a human rights-based approach needs to be used more within the service, and staff should be made aware that this approach will support them in adhering to legislative requirements.

Participants discussed the need for front-line staff to be supported during any culture shift towards a human rights-based approach in order to ensure the adoption of new practices. They were of the view that staff need clear guidance on respecting a person's rights, involvement in decision-making and what good communication

looks like. They felt that the outcomes of working in this way also need to be clearly explained.

Focus group participants highlighted the need for practitioners to have their human rights respected and promoted also, and noted the need to balance the rights of the person using services with the rights of the practitioner.

In relation to what the guidance should look like, participants emphasised that the guidance should be written in plain English and include details of what human rights are, as well as provide practical examples (both positive and negative) that are applicable to different disciplines and settings. They noted that the guidance should be relevant for people using services and their family, friends and advocates, in addition to service providers and practitioners.

Participants suggested that helpful tools be included in the guidance, such as a basic self-assessment toolkit and a flow chart that could be used as a quick reference to understand how to manage a particular human rights issue. In addition, participants suggested other useful resources be developed to accompany the guidance, for example a poster and tri-fold leaflet outlining the key messages from the guidance, and an e-learning module like the 'Children First' module.

4.2 Feedback from review focus groups (held during the public consultation on the draft guidance)

Three focus groups were held during the public consultation in order to obtain feedback from people using services, advocates and staff on the draft guidance. Those who participated in the earlier focus groups were contacted again and invited to participate in additional focus groups to provide feedback on the draft guidance. A summary of the points raised during these focus groups are detailed below. In advance of the focus groups, all participants were sent a copy of the draft guidance to review. At the focus groups, participants were asked their views on the draft guidance and feedback was categorised according to the relevant sections of the document. Additional points raised that did not fall within these categories were identified and are also reported below.

There was substantial overlap between the feedback received from the focus groups and the feedback received from the public consultation. Therefore, this section of the report focuses on the points raised by the focus group members that are not covered in the following chapter on the findings from the public consultation.

Introductory section

The scope of the guidance was discussed by the groups and participants suggested that the scope be clarified further in the introductory section. A number of participants felt that the document should make reference to the human rights of staff, in addition to the rights of people using services.

FREDA Principles

Feedback in relation to the FREDA principles is outlined below under the relevant principle.

Fairness

Participants discussed the difficulties involved in providing complete and accessible information to people using services in situations where a person lacks capacity or does not want to receive full information about their health status.

The challenges involved in promoting a restraint-free environment in some services was discussed, in particular when the safety of the person, other people or staff was a concern. The importance of due process and collective working as a team when making decisions in relation to restrictive practices was noted by a couple of participants.

The importance of supporting individuals using a service to provide feedback and to make a complaint was highlighted by the groups. A number of participants noted that services should be responsible for addressing any complaint in a timely manner and that inspections of services should assess for this.

Respect

Participants felt that the guidance should highlight that people using services have a right to receive information in a format appropriate to their communication needs and preferences, and to be supported and enabled to express their will and preferences. It was highlighted by a small number of participants that in some care settings, people using services are extremely reliant on resources to achieve their person-centred goals.

Equality

A number of participants requested that this section mention particular groups at risk of discrimination.

Dignity

Focus group participants requested that the guidance contain more detail in relation to ensuring that a person's basic needs are met, to include wider needs, for example the need to feel comfortable, warm and respected.

A number of participants highlighted the impact that limited resources can have on the ability of staff to meet the basic needs of people in residential care settings and discussed current practices in other settings which impact on the dignity of people using services and the wellbeing of staff. Providing supports to staff, and to people using health and social care services, to support their wellbeing was felt by participants to be important.

A number of participants highlighted the importance of ensuring that the guidance is aligned with other HIQA documents on restrictive practices.

Autonomy

Feedback in relation to autonomy highlighted that autonomy is not an 'inalienable right' and respecting autonomy can be a grey area in practice. In relation to seeking consent, a number of participants reiterated that not all people using a health or social care service wish to receive information on their care.

Case studies

Overall, participants appreciated the practical examples of rights. Suggestions for additional case studies included where the concern was one of safeguarding, or where a person's rights were restricted and later reinstated. It was also suggested that the role of an advocate be included in some of the case studies. In addition, participants suggested minor amendments to a number of the case studies to ensure the scenarios were true to life.

Resources

A number of participants suggested Resource 1 could be more practical by providing examples and contextualising situations wherein these rights occur. A number of suggestions were made for enhancing Resource 2, for example providing a blank version of this resource that staff can use in their work. Participants suggested the inclusion of an additional resource with further information on issues that could not be explored in the guidance.

Language and layout

Overall, there was a consensus amongst focus group participants that the guidance was easy to read and well laid out. Participants welcomed the lack of jargon in the guidance and felt it lended itself well to those whose first language was not English.

There were requests to change the use of the term 'my service' throughout the guidance to a more person-centred term, such as 'the service I work in.' Participants requested that the language be strengthened in specific places in the guidance to ensure the relevant points would not be lost.

Challenges

A number of participants noted that the role of the organisation that is providing the health and or social care service was missing from the document. They noted that it is the responsibility of the organisation to support staff in implementing this guidance and to have a policy in place for this. The importance of adequate resources, time and management support to enable staff to implement this approach was highlighted. The question 'how do we deliver this kind of care if we do not have resources and time?' was asked.

How this feedback informed the development of the guidance

Notes from each of the focus groups were read in their entirety and each individual comment was assessed to determine whether or not it would be incorporated into the draft guidance. All comments were reviewed by the Project Team alongside the feedback received from the public consultation and subsequent changes to the draft guidance were agreed.

In addition to the guidance, HIQA is developing a broader suite of materials to promote the concept, principles and practice of a human rights-based approach to care and support to assist staff in health and social care services. Feedback received on the draft guidance from the focus groups and the public consultation will be considered, alongside feedback received through other consultations with informed and interested parties, to inform the development of the additional resources.

Chapter 5 Analysis of the public consultation

5.1 Overview of the public consultation submissions

All of the feedback received from the public consultation was analysed and collated by the Project Team under the relevant sections of the draft guidance.

There were 75 responses received over the six-week public consultation period. Of the 75 submissions received, 53% (n=40) emailed their submissions; 43% (n=32) were received via the online survey tool; and 4% (n=3) were received by post.

Each submission received was read in its entirety and each individual comment was assessed to determine whether or not it would be incorporated. All submissions were reviewed by the Project Team and subsequent changes to the draft guidance agreed. While this statement of outcomes document is not an exhaustive record of all comments received, it highlights some of the key items raised by people during the public consultation.

The consultation comprised of five specific questions relating to each section of the draft guidance, along with six general feedback questions. The aim of these general and specific feedback questions was to elicit public opinion on the draft guidance. This chapter provides an overview of the submissions received for each question.

In the 'About you' section, respondents were asked if they were commenting on behalf of an organisation or in a personal capacity. If they were making the submission on behalf of an organisation they were asked to include the name of the organisation. Respondents were also asked whether they were commenting as a person who has used health and social care services or as a staff member or other person working in a health and social care service. Respondents who worked in a health or social care service were asked to specify their role. Respondents making a submission on behalf of an organisation were asked to provide contact details so that these submissions could be verified.

5.2 Results of the consultation submissions

Of the 75 responses, 23 people (31%) responded in a personal capacity and 51 people (69%) responded on behalf of an organisation. Figure 2 outlines responses received from individuals or on behalf of an organisation.

Of the 66 respondents who answered the question:

- 37 (56%) stated that they were providing feedback as a staff member or other person working in a health or social care service

- four (6%) stated they were commenting as a person who has used or is currently using a health or social care service and
- 25 (38%) stated they were commenting in an 'other' capacity.

Figure 2. Responses to consultation



Fifty respondents (67%) gave details of their roles. Examples of the roles of respondents working in health and social care services include:

- CEO (Charity)
- Clinical nurse manager
- Director of nursing
- Head of advocacy
- Mental health counsellor
- Person in charge
- Quality and compliance manager
- Residential services team leader
- Speech and language therapy manager
- Staff nurse.

See Appendix F for examples of the types of organisations that made submissions to the public consultation.

5.3 Feedback questions on specific sections of the draft guidance

In this section of the feedback form, respondents could provide feedback on the content of each section of the draft guidance. Respondents were asked to consider the following questions as part of their review:

- Do you think all important areas have been covered under each principle or are there any areas that should be included or excluded?
- Are the case studies included in each section sufficient to assist staff working in health and social care services understand a human rights-based approach to care and support?

When providing their feedback, respondents were asked to reference the section and page number that they were commenting on.

5.4 Feedback on the Overview of human rights

The majority of respondents (92%, or 69 people) provided comments on the introductory section of the draft guidance.

What the respondents said

While setting out the legal framework underpinning human rights was welcomed for giving the necessary weight to the guidance, a small number of respondents requested a greater level of detail be provided on the international and national legislation underpinning human rights. Suggestions were made to include a number of additional treaties, charters, and acts, for example the Universal Declaration of Human Rights and the EU Charter of Fundamental Rights. Including the Public Sector Equality and Human Rights Duty set out in Section 42 of the Irish Human Rights and Equality Commission Act 2014 was considered important, as it is a legal obligation of many health and social care staff.

It was noted that the guidance mainly focuses on the individual staff member and that team working is important in health and social care services. It was highlighted that decisions pertaining to restrictive practices are made by a team rather than by individual staff members.

Respondents highlighted that it is the responsibility of the organisation as well as staff to uphold the human rights of people using services. It was also noted that the human rights of staff need to be considered.

Feedback included that providing health and social care can be a complex endeavour and that upholding human rights is not always straightforward in practice and it was suggested that the guidance acknowledge this.

HIQA's response

The introduction section has been revised to highlight that the guidance will help staff to comply with their obligations under the Public Sector Equality and Human Rights Duty as set out in Section 42 of the Irish Human Rights and Equality Commission Act 2014. In addition to the guidance, HIQA is developing a broader suite of materials to promote the concept, principles and practice of a human rights-based approach to care and support to assist staff in health and social care services. Further detail on the international and national legislation underpinning human rights will be provided in these resources.

Reference to team working, and to collaboration with all parties involved in a person's care and support, have been added to this section.

This section has also been revised to make clear the responsibility of organisations to uphold the human rights of people using services.

The purpose of this guidance is to support staff to protect, promote and support the human rights of people they provide care and support to. HIQA acknowledges the importance of the rights of staff working in health and social care services, and high-level reference to the rights of staff has been added to the introduction to the guidance. In addition, HIQA will consider this feedback, along with that received from other consultations with informed and interested parties, to inform the prioritisation and development of resources in this area.

Additional text has been added to this section to acknowledge the complexities of upholding human rights in situations where many factors or competing rights need to be considered by staff.

5.5 Feedback on the FREDA principles

The majority of respondents (91%, or 68 people) provided comments on the FREDA principles.

There was overall agreement with the use of the FREDA framework to underpin the guidance. A small number of respondents noted that the PANEL framework may have provided a more operational approach to human rights. The PANEL framework is one way of breaking down what a human rights-based approach to care means in practice. PANEL stands for: Participation, Accountability, Non-discrimination and equality, Empowerment, and Legality. Both the PANEL framework and the FREDA

framework were considered at the initial stages of the guidance development process and the FREDA framework was chosen as it emerged from the evidence review.

There were multiple requests to align the guidance, and the FREDA principles in particular, with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). In response to this feedback, each of the five FREDA principles has been linked to the relevant articles within the UNCRPD, in addition to the European Convention on Human Rights (ECHR).

Fairness

What the respondents said

Feedback from a small number of respondents highlighted that the language used in this section portrayed the person using services as passive within the decision-making process and that the guidance should make clear that decisions about a person's care and support should be made by the person using the service, rather than simply involving the person in the decision-making process.

Requests were made to further highlight the right of people to receive information in a format and medium appropriate to their needs and preferences, and the responsibility of staff to support people to express their will and preferences.

It was suggested that the guidance highlight that staff should comply with the wishes of the person using the service in relation to sharing of information with family members, and that consent should be obtained when sharing information.

Respondents noted that it is important to encourage people using services to provide feedback, both positive and negative, and that complaints should always be addressed promptly. Facilitating access to an independent advocate when making a complaint was also considered important by respondents.

HIQA's response

The definition of Fairness and the section on 'How can I uphold fairness in my day-to-day work?' have been strengthened to reflect that the person using the service is at the centre of any decision-making process regarding their care and support.

The circumstances under which personal information may be shared with others and the importance of consent have been further clarified in the text.

Sections relating to communication here and throughout the guidance have been strengthened to highlight how staff should provide information in a format and medium appropriate to the individual's communication needs and preferences; and

support people to access information and to communicate their will and preferences through a variety of media.

The section on supporting a person to make a complaint has been expanded to include positive as well as negative feedback, access to support services, and to highlight the importance of following up on behalf of the person making a complaint to ensure that the complaint is responded to promptly, openly and effectively.

Respect

What the respondents said

A small number of respondents stated that the guidance should further emphasise the importance of involving people using services in service planning and development, in addition to decisions around their own care and support.

Respondents noted that the guidance needs to reflect the needs of those with communication difficulties and those whose first language is not English.

The need for staff to recognise the evolving nature of a person's goals, and for their care plan to reflect their up-to-date will and preferences, was highlighted by respondents.

Feedback said that it would be helpful if the guidance addressed measures staff members should take if they observe a human rights violation.

HIQA's response

The text was strengthened to emphasise the importance of involving people using services in service design and development.

In response to the feedback that the guidance needs to reflect the needs of those with communication difficulties and those whose first language is not English, the role of an advocate or interpreter in supporting communication with people using services has been added.

The text was revised to highlight the importance of regularly reviewing a person's goals, and ensuring that their up-to-date will and preferences are reflected in the planning of their care and support.

Additional text has been added to this principle to highlight the importance of staff seeking advice and support if they observe or are concerned that a person's human rights are not being upheld. An additional resource has also been added to the guidance to provide useful contacts for staff if they need further information and support outside of the service they work in.

Equality

What the respondents said

A high number of respondents requested that the definition of equality reference the equality grounds under the Equal Status Acts 2000-2015, rather than the grounds under the ECHR, as the former are used in day-to-day law in Ireland. This point was reiterated in relation to the grounds for discrimination cited throughout the other principles.

Some respondents questioned whether use of the terms 'equal access to care and support' and 'equal outcomes from care and support' was appropriate in this context and whether it should more appropriately be 'equitable access' and 'equitable outcomes.'

Supporting people in their right to vote and their right to have valued roles within cultural, social, political and other organisations was noted by respondents to be an important element of supporting a person's participation in society.

HIQA's response

In response to requests to reference the equality grounds listed in the Equal Status Acts 2000-2015, changes have been incorporated to this section and throughout the guidance to reflect the nine grounds for discrimination within the Equal Status Acts 2000-2015.

Changes have been made to the introduction section to explain the concepts of 'equality' and 'equity' and their role in supporting people using services to achieve the best possible outcomes from care and support, regardless of their status or characteristics.

The text has been strengthened in relation to 'promoting participation in society', to include supporting the person in their right to vote and to have valued roles within political, religious, social, cultural and self-help or advocacy organisations.

Dignity

What the respondents said

The importance of addressing a person using services by their preferred gender, in addition to their preferred name, was noted by a small number of respondents.

Feedback received highlighted that others may need to be consulted regarding a person's preferences for their personal care in situations where the person is no longer able to communicate their wishes.

HIQA's response

The importance of addressing a person by their preferred gender pronoun has been incorporated within this principle.

In relation to supporting a person's preferred lifestyle, the text has been elaborated to include consulting with others who know the person to ascertain their past and present preferences where a person's preferred lifestyle is not easily known.

Autonomy

What the respondents said

It was requested that the guidance address how family members can sometimes exert undue influence on a person's decisions and the difficulties for staff in promoting a person's right to autonomy in this situation.

A small number of respondents suggested that the guidance include the need to support a person to increase their capacity to make an informed decision, as this is a key aspect of the work of staff in social care services.

The importance of encouraging a person to participate in the planning of their care and support, and recognising that the person's wish to engage with this process can change over time, was highlighted by respondents.

HIQA's response

The importance of staff seeking advice and support if they observe or are concerned about undue influence on a person's decision-making has been added to this principle.

The need to support a person to increase their capacity to make an informed decision, or reduce a restriction through skills development, has also been added to the text.

In relation to a person's participation in their care planning, the text has been revised to reflect the person's right to engage as much as they wish. Where the person chooses not to engage, the need to review their interest to re-engage over time has also been included.

5.6 Feedback on the case studies

The majority of respondents (84%, or 63 people) provided comments on the relevance of the case studies to people working in health and social care services.

What the respondents said

Overall, the response to the case studies was positive, with respondents noting that they made the FREDA principles meaningful and brought the guidance to life. Many respondents noted that the case studies had relevance for many health and social care settings. A small number of respondents felt the case studies were not reflective of the complexities they encounter in their practice, or that their area of practice was not represented in the range of settings included in the case studies, for example addiction services, speech and language therapy, and acquired brain injury.

Other feedback received included:

- suggestions to emphasise the time and resource investment required in upholding a person's rights in particular case studies,
- specifying the particular human rights affected in a number of the case studies,
- and ensuring the content of the case studies aligned with the presumption of capacity set out in the Assisted Decision-Making (Capacity) Act 2015.

HIQA's response

The purpose of the case studies is to illustrate the FREDA principles by providing context for staff, and they are not intended to replace professional judgement. HIQA recognises that health and social care can be a complex endeavour and that further advice may need to be sought when certain situations relating to human rights arise in a service. HIQA acknowledges the request for more complex case studies from a wider range of settings and will incorporate a broader range of settings and more complex case studies in the broader suite of resources being developed to complement the guidance.

Changes were made to specific case studies to align the content with the presumption of capacity set out in the Assisted Decision-Making (Capacity) Act 2015, to highlight the human rights involved, and the time and effort required to support these rights.

5.7 Additional case studies

The majority of respondents (80%, or 60 people) provided suggestions for types of case studies that could be included in the guidance.

What the respondents said

A few respondents felt there was an over-emphasis on older person's and disability services in the case studies featured in the guidance. Respondents requested that their area of expertise be featured in the case studies, for example mental health, addiction, acquired brain injury and asylum seekers. Respondents also requested more complex case studies.

HIQA's response

HIQA acknowledges the request for a wider range of settings to be featured in the case studies and will incorporate a broader range of settings and more complex case studies in the broader suite of resources being developed to complement the guidance.

5.8 Resources

Almost three-quarters of respondents (71%, or 53 people) provided comments on the resources provided in the document.

What the respondents said

Overall, respondents welcomed the resources provided in the draft guidance and considered them concise, informative and helpful. Respondents stated that Resource 1 summarising the key human rights in the ECHR would be a valuable reference document. A small number of respondents requested that human rights from other important conventions and charters be incorporated into the resource, for example the UNCRPD, the European Charter of Patients' Rights, and the Universal Declaration of Human Rights. It was noted that linking these rights back to the FREDA principles would be useful.

Respondents thought that the decision-making aid in Resource 2 would be particularly useful for staff in their day-to-day practice. A small number of respondents suggested elaborating on this resource, for example by including an example where a right was restricted and subsequently reinstated or where the rights of one person compete with those of another. Including a similar resource with an example from a social care setting or having a library of flow charts for the most common scenarios in each type of health and social care setting were also suggested.

Requests were made to include an additional resource which directed staff to relevant organisations should they have a concern in relation to a human rights violation. An easy-to-read version of the guidance was also requested to enable people using services to better understand human rights.

HIQA's response

Resource 1 has been revised to incorporate key human rights from the UNCRPD and to link these rights and those within the ECHR to the FREDA principles.

The purpose of Resource 2 is to provide a generic decision-making aid that may be used in a range of situations and settings; the example provided therein is for illustrative purposes only. HIQA acknowledges the requests for more tailored examples and an easy-to-read version of the guidance for people using services, and will consider these in the development of additional resources to complement the guidance.

An additional resource has been added to the guidance to provide further reading if staff want further information in relation to human rights, and useful contacts if staff have a concern about the human rights of a person using the service they work in.

5.9 General comments on the draft guidance

Are there any other general comments or suggestions on the draft guidance that you would like to make?

This question gave respondents the opportunity to provide further general comments on the draft guidance. Over three-quarters of respondents (79%, or 59 people) answered this question.

What the respondents said

The feedback was generally positive and the publication of the draft guidance was viewed as a welcome development. Some examples of what respondents said include:

'This guidance will be a very effective guidance in guiding staff as to how they themselves are having their human rights protected, but also to ensure that the service users are having their human rights protected through effective care planning and work practices.'

'The document is really well written, informative and a great resource for training staff and also for informing residents of their rights in a different format.'

"This document obviously took a lot of time and research which will benefit any person who reads it whether they work in a health care setting or not.'

'We found it a very easy tool to use and potentially implement.'

However, a number of respondents, while welcoming the guidance, highlighted the need for additional resources and implementation supports to enable staff to put this approach into practice:

'With any policy being implemented, adequate funding and resources must be provided to ensure health and social care services can properly implement any policies.'

'Front line staff are usually time limited and bombarded with policies - the human rights-based approach toolkit needs to be supplemented with workshops or training to be of benefit.'

Suggestions were also made for an accompanying guidance or an easy-to-read version for people using services, especially people with cognitive or communication difficulties.

A number of submissions asked how this guidance will interact with the Assisted Decision-Making (Capacity) Act 2015, which is currently in the process of being enacted.

HIQA's response

HIQA is developing a broad suite of materials to promote the concept, principles and practice of a human rights-based approach to care and support to assist staff in health and social care services. HIQA is considering the suggestions received through the public consultation, along with that received through other consultations with informed and interested parties, in order to inform the prioritisation for development of additional resources to complement this guidance. An information leaflet for people using services will be taken into consideration for further resources to accompany the guidance.

HIQA has collaborated with the Decision Support Service to ensure that the relevant sections of the guidance are aligned with the requirements of the Assisted Decision-Making (Capacity) Act 2015. While it is not the purpose of the guidance to provide detailed information on the requirements of this Act, HIQA acknowledges the requests for further guidance in this area and has provided this feedback to the Decision Support Service.

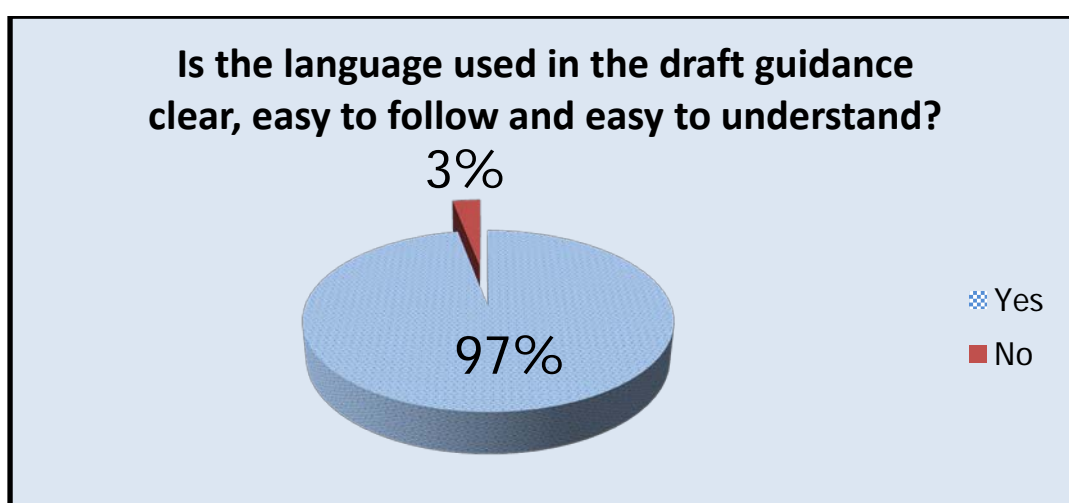
5.10 Feedback on the language, content and structure of the draft guidance

Questions 3.1(a), 3.1(b) and 3.2 asked for feedback on the language, content and structure of the draft guidance. This section of the document provides an overview of the responses received in relation to these questions.

Language used in the draft guidance

This question asked respondents to state whether the language used in the draft guidance is clear, easy to follow and easy to understand. Sixty-five respondents (87%) answered this question. Of those who did provide feedback to this question, 63 people (97%) stated that the language used in the draft guidance is clear, easy to follow and easy to understand. Figure 3 shows the number of Yes or No responses for whether the language used in the draft guidance is clear, easy to follow and easy to understand.

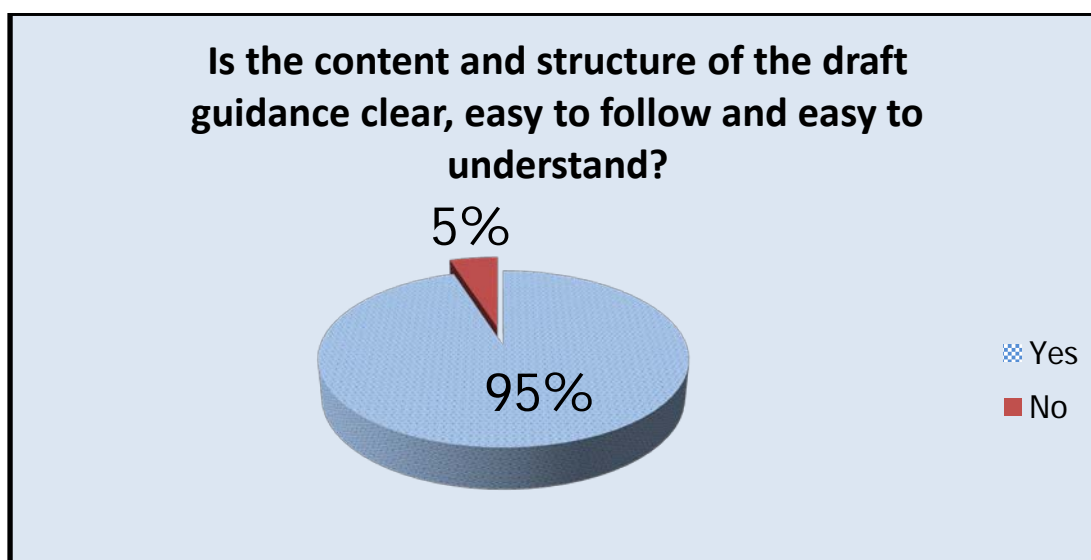
Figure 3. Responses to consultation question regarding language used in guidance



Content and structure of the draft guidance

This question required respondents to state whether the content and structure of the draft guidance is clear, easy to follow and easy to understand. Sixty-five respondents (87%) provided feedback on this question. Of the respondents who answered the question, 62 respondents (95%) stated that the content and structure of the draft guidance is clear, easy to follow and easy to understand. Figure 4 presents the number of Yes or No responses for whether the content and structure of the draft guidance is clear, easy to follow and easy to understand.

Figure 4. Responses to consultation question regarding content and structure of guidance



What the respondents said

Forty-one respondents (55%) provided additional comments on the language, content and structure of the draft guidance. Overall, the comments made were positive and included:

'Very clear and precise language and structure. The case studies are very effective in helping to understand how to bring a human rights approach into the workplace.'

'I found language, content and structure was user friendly, easy to comprehend, relevant to current practice.'

'Language is good, not too technical, not oversimplifying tricky issues.'

However, a number of respondents noted that the document would not be accessible to all people using services and an easy-to-read guide should be considered.

'There is a need to have an easy to read version relating it to people being supported by our services.'

'If consideration is given to making this accessible to service users, a number of versions should be produced to ensure that it is accessible to everyone.'

5.11 Understanding, impact and usefulness of the guidance

Questions 3.3, 3.4 and 3.5 focused on understanding, impact and usefulness of the draft guidance. This section of the document provides an overview of responses received in relation to these questions.

Understanding of human rights

Having read the draft guidance, do you have a better understanding of human rights and how they apply to your work?

Forty-four people (59%) responded to this question. Of those who answered the question, 40 respondents (91%) stated that they had a better understanding of human rights and how they applied to their work, having read the draft guidance.

What the respondents said

There was an overarching agreement that the draft guidance had improved respondents understanding of human rights and a human rights-based approach to care and support. Examples of comments received include:

'Yes, the document highlights how actions by staff in social care settings have human rights implications on areas such as decision-making, client empowerment and choice.'

'Organisationally, this information will support a better understanding of human rights.'

'Yes, this guidance will certainly enhance the understanding of human rights for staff, and make human rights more real for staff in the context of their workplaces.'

'Yes, the guidance offers a useful tool for reflecting on practice and promoting Continuous Professional Development.'

A number of respondents stated that reading the draft guidance had made them view their work in a new light.

'Yes it got me thinking and while I was happy enough with how I uphold people's human rights within my own care practice, I know it's an area that needs constant reflection/discussion within staff teams.'

'Having read the guidance I have more questions and critique of how human rights can best be meaningfully practiced in practice situations.'

Most respondents who answered no to this question stated that the guidance had not added to their understanding as they were already very much aware of human rights and practiced a human rights-based approach in their work. Examples of comments received include:

'I'm answering No to this question as I already feel very much aware of each person's human rights and the importance of ensuring that all staff support each resident in the upholding of their human rights and dignity.'

'I am professionally and personally interested in this issue i.e. human rights. No better understanding following draft guidance. Draft would improve understanding of someone with less interest that I have.'

Intention to change

Having read the draft guidance, do you intend to make changes to your work practices?

Forty-six people (61%) responded to this question. Some people who did not provide an answer to this question stated that they did not have any direct involvement with the provision of health and social care in Ireland. Of the respondents who answered the question, three-quarters (76%, or 35 people) stated that they intended to make changes to their work practices having read the draft guidance.

What the respondents said

Overall, feedback was positive with regard to respondents' intention to change their work practices. Some of the areas in which respondents intended to make changes included: incorporating the guidance as part of staff induction and training, using the guidance to inform team meetings and to educate people using services, and changing the way risk assessments are conducted.

'This guidance document will be very helpful in assisting staff to implement/respond to Theme 1 of the National Standards for Safer Better Care but also as a resource in providing care across all services. We will incorporate this in our PPPG training for the development of documents going forward and also suggest it form part of MDT meetings where decisions on care are being discussed.'

'Provide education to the residents, relatives and staff to ensure everyone is fully informed and aware of the importance of upholding the Human rights and Dignity of

each resident. While also supporting the relatives and staff members to exercise their human rights.'

'Consideration of the FREDA principles in certain situations and inclusion of the case studies as examples when educating staff.'

'The guide when published is a tool I will use with staff inductions etc.'

'Yes, I will introduce the FREDA principles to our staff team at one of our regular staff team meetings and look at improving the involvement of people in assessing their risks.'

Others who answered that they did not intend to change their work practice stated they had already incorporated a rights-based approach in their work.

Usefulness of the guidance

Do you think this guidance will be a useful resource for people working in health and social care services?

Three-quarters of respondents (76%, or 57 people) answered this question. Of those who answered the question, almost all (96%, or 55 people) stated that the guidance will be a useful resource.

What the respondents said

In general, respondents welcomed the guidance as a valuable resource to support the work of staff in health and social care services, and bring clarity and improvement to their practice. Feedback indicated that the guidance will be a useful training resource and self-assessment tool for staff, as well as an educational resource for people using services and their families. Many respondents indicated that the guidance will be a useful reminder even for those who feel they are already implementing a human rights-based approach. Others noted this guidance will help staff to implement human rights legislative requirements into their practice, for example the UNCRPD and the Assisted Decision-Making (Capacity) Act 2015. Examples of comments received include:

'Very helpful tool to assist staff to provide person-centred care. The case studies give clear live examples which makes the application of the FREDA principles very clear. A very useful Guidance Document which will have far reaching implications on how services should be provided and assist in embedding this approach in their everyday work. Applying the FREDA principles to understanding the barriers facing

people using our services, their needs and views, acknowledging and accommodating difference and not treating everyone the same.'

'We always need reminders as to how we should treat others, practice humanely in accordance to 'natural laws' as a buffer to slipping into malpractice.'

'While the ethos in a Nursing Home may be based on a Human Rights Approach it will be a useful tool when providing education and information to the residents, family members and staff.'

'There is a huge need for more information, training and understanding of human rights approach in services so that we can begin as a nation to implement the UNCRPD and make rights real on the ground. This document, accompanying accessible information, tools, and resources will help these endeavours greatly.'

However, a number of comments alluded to the limited range of health and social care settings included in the case studies. The importance of having a dissemination plan for the guidance was highlighted, as well as the need for additional training and resources to support its implementation.

'No, the examples provided are very limited to older people and people with intellectual disabilities. No guidance is provided for people with other disabilities - visual, hearing, psycho-social, sensory disabilities or neurodivergent people.'

'The finished product hopefully will be useful once it is disseminated correctly to staff at all levels and doesn't gather dust on a shelf.'

HIQA's response

The purpose of the case studies is to illustrate the FRED A principles by providing context for staff. However, HIQA acknowledges the request for a wider range of settings to be featured in the case studies and will incorporate a broader range of settings and more complex case studies in other resources being developed to complement the guidance.

An extensive dissemination plan has been developed by HIQA to raise awareness of the guidance and to ensure it is disseminated as widely as possible to staff in health and social care services.

HIQA is developing a broader suite of materials to promote the concept, principles and practice of a human rights-based approach to care and support to assist staff in health and social care services. Suggestions regarding tools and resources to support the implementation of the guidance received through the public consultation will be

considered, along with those received through other consultations with informed and interested parties, in order to inform the prioritisation for development of additional resources.

Chapter 6 Conclusion and next steps

Both the focus group feedback and public consultation submissions were reviewed and considered and the draft guidance was revised based on the feedback received.

A summary of the feedback and subsequent changes to the draft guidance was presented to the Advisory Group at its final meeting on 21 August 2019; the revised guidance was then subsequently approved by the Director of Health Information and Standards.

The *Guidance on a Human Rights-based Approach in Health and Social Care Services* was published by HIQA on 13 November 2019. HIQA would again like to thank all those who contributed to the development of this guidance through the Advisory Group, focus groups and the public consultations. This involvement helped ensure that the guidance is appropriate to the Irish context and can be implemented in practice. This will help contribute to the improvement of health and social care services for people using these services.

Appendix A – Membership of the Advisory Group and the HIQA Project Team

Advisory Group

Name	Organisation
Áine Flynn	Director, Decision Support Service
Ann Marie O'Boyle	Investigator, The Office of the Ombudsman
Anne Dempsey	Communications Manager and Training Facilitator, Third Age Ireland
Anne O'Loughlin	Principal Social Worker, Irish Association of Social Workers
Asim Sheikh	Barrister-at-Law and Assistant Professor, Law Library and University College Dublin School of Medicine
Catherine Cox	Head of Communications and Carer Engagement, Family Carers Ireland
Christine Barretto	Social Care Worker, Cheeverstown House Community Services, Social Care Ireland
Ciara McShane ³	Regional Manager (Disability Pillar), Health Information and Quality Authority (HIQA)
Donal Hurley	Principal Social Worker, National Safeguarding Office, Health Service Executive
Eibhlin Byrne	Director Quality Assurance, Irish Refugee Protection Programme, Department of Justice and Equality
Emma Balmaine	Chief Executive, St. John of Gods, Private Hospitals Association
Iris Elliott	Head of Policy and Research, Irish Human Rights and Equality Commission
Liam Herrick	Executive Director, Irish Council for Civil Liberties
Mark Felton	Solicitor, The Law Society
Mark O'Connor ⁴	Community Engagement Manager, Inclusion Ireland
Martin Keville	Assistant Principal Officer, Department of Social Protection
Mary Condell	Legal Advisor, Sage

³ From January 2019 – May 2019

⁴ From August 2019

Noeleen Byrne	Assistant Inspector, Mental Health Commission
Padraig McLoone	Risk and Incident Compliance Officer, Health Service Executive
Phelim Quinn ⁵	CEO, HIQA
Rachel Flynn	Director of Health Information and Standards, HIQA
Ray Lynch ⁶	Inspector (Disability Pillar), HIQA
Rosemary Smyth	Director Standards and Quality Assurance, and Director Training and Development, Mental Health Commission
Ruth O'Reilly	Senior Standards Officers, National Disability Authority
Sarah Lennon ⁷	Interim CEO, Inclusion Ireland
Sinead Morrissey	Practice Development Facilitator, Nursing Homes Ireland
Siobhan O'Sullivan	Chief Bioethics Officer, Department of Health
Vicky Blomfield	Head of Quality, HIQA

HIQA Project Team

Name	Title
Aidan Murray	Subject Matter Expert
Davina Swan ⁸	Standards Development Lead
Laura Behan	Standards Development Officer
Linda Weir	Standards Manager

⁵ Chairperson

⁶ From May 2019

⁷ From January 2019 – June 2019

⁸ From April 2019

Louise Dolphin ⁹	Standards Development Officer
Niamh O'Rourke ¹⁰	Head of Standards
Shauna McCarthy ¹¹	Standards Development Officer
Suzanne Barror ¹²	Standards Development Lead

⁹ From July 2018 – January 2019

¹⁰ From April 2019

¹¹ From March 2019

¹² From November 2018 – June 2019

Appendix B — Scoping Consultation Feedback Form

Guidance to support a rights-based approach in health and social care services for adults



Scoping consultation feedback form

3 October 2018

The Health Information and Quality Authority (HIQA) is developing guidance to support a rights-based approach in health and social care services for adults. This guidance aims to promote awareness among management and practitioners in health and social care settings about delivering care in a way that promotes a rights-based approach.

We are holding a scoping consultation early in the process to give people an opportunity to identify the key areas that this guidance should address and to provide examples of good practice.

We will carefully assess all feedback received and use it, along with other available evidence, to develop the guidance.

Before you complete this consultation feedback form, please read the accompanying **brief** available at www.hiqa.ie and the instructions for submitting feedback on the next page.

The closing date for the scoping consultation is 5pm on 31 October 2018.

Instructions for submitting feedback

- If you are commenting on behalf of a service or organisation, please combine all feedback from your organisation into one submission form and include the details of the service or organisation. When completing this form online, please ensure you scroll down the webpage and complete the form in full.
- Do not paste other tables into the boxes already provided — type directly into the box as the box expands.
- Please spell out any abbreviations that you use.

Data Protection and Freedom of Information

Please note, your feedback will be treated in compliance with the Data Protection Act 2018. HIQA will only collect personal information during this consultation for the purposes of verifying your feedback or where you have indicated that you would like to be contacted to partake in future engagement opportunities. If you have any concerns regarding your data, please contact InfoGovernance@hiqa.ie.

Furthermore, HIQA is subject to the Freedom of Information (FOI) Act 2014 and the statutory Code of Practice in relation to FOI. If we receive a request for disclosure of the information under FOI, while we will take full account of requests for confidentiality, we cannot give you an assurance that it will be maintained in all circumstances. Following the consultation, we will also publish a Statement of Outcomes report summarising the responses received. The Statement of Outcomes will include the names of organisations that submitted feedback to us.

1. About you

The feedback in your consultation form will only be used to help develop the draft guidance to support a rights-based approach in health and social care services for adults. Any information you provide will be held securely and will not be published, subject to legal requirements under Freedom of Information (FOI) legislation.

Please tick as appropriate:

Question 1: Are you providing feedback as:

an individual

on behalf of an organisation:

(For verification purposes, please provide the name of the organisation and a name and landline contact number for a contact person within the organisation.)

Please tick as appropriate

Question 2: Are you commenting as:

a person who has used or is currently using health and social care services

a staff member or other person working in a health and social care service

(Please specify your role)

other

(Please specify)

2. Feedback to inform the draft guidance

In this section, we would like to hear what you think are the key areas that the guidance should address, what key sources of information should be reviewed, and who we should engage with during the development process.

Question 3: What are the key areas that the guidance should address?

(Please indicate why they are important)

Question 4: What are the key sources of information that we should review to inform the development of the guidance?

(Key sources of information could include national and international peer-reviewed literature, policy, legislation, standards, tool-kits, guidelines and guidance)

Question 5: What key organisations or individuals, within this sector, should we engage with, when developing the guidance?

(We may invite them to take part in future focus groups or to comment during the consultation on the draft guidance)

3. Register to hear about future engagement opportunities

Question 6: Would you like to hear about opportunities to engage with us on the development of this guidance or on other future projects?

(This may include an invitation to focus groups or to comment during the consultation on the draft guidance)

Yes **No**

Please provide your name and contact number.

Thank you for taking the time to give us your views on the development of guidance to support a rights-based approach in health and social care services for adults.



You can **download** a consultation feedback form at www.hiqa.ie

Then **email** the completed form to standards@hiqa.ie.

or



Print the consultation feedback form and **post** the completed form to:

**Draft Guidance on Rights-Based Care
Health Information and Quality Authority
Unit 1301,
City Gate,
Mahon, Cork,
T12 Y2XT.**



If you have any questions on this document, you can contact the standards team either by:

phoning: **(021) 240 9300** or

emailing: **standards@hiqa.ie**

Please ensure that you submit your form online or return it to us either by email or post by 5pm on 31 October 2018.

Appendix C – Organisations that made submissions to the scoping consultation

Organisations that responded to the scoping consultation (October 2018):

- Ability West
- Age Action
- COPE Galway
- Disability Federation of Ireland
- Family Carers Ireland
- Health Information and Quality Authority
- HSE Addiction Service
- HSE Antimicrobial Resistance and Infection Control Team
- HSE Assisted Decision Making National Office
- HSE National Safeguarding Office
- Lusk Community Unit
- Migrant Rights Centre Ireland
- National Advocacy Service for People with Disabilities
- National Federation of Voluntary Bodies
- National Rehabilitation Hospital
- Office of the Ombudsman
- RehabCare
- South East Regional Drug and Alcohol Task Force
- St John of God's Kerry Services
- St Margaret's Donnybrook
- St Michael's House
- St Patrick's Mental Health Services

- The Irish Society of Chartered Physiotherapists
- The Irish Wheelchair Association
- University College Dublin

Appendix D – Schedule of questions for focus group discussions

Questions for scoping focus groups

1. What is your understanding of a human rights-based approach to health and social care?
2. What has been your overall experience of implementing a human rights-based approach in your work?
3. Can you think of specific case studies or examples from your work that could help illustrate examples of good practice?
4. How do you think this guide could be useful to you and your colleagues?

Questions for review focus groups during public consultation

1. Do you think this guidance will be a useful resource for people working in health and social care services?
2. What are your thoughts on the introductory sections of the guidance?
3. Do you think all important areas have been covered under each principle or are there any areas that should be included or excluded?
4. Are the case studies included sufficient to assist staff working in health and social care services understand a human rights-based approach to care?
5. Do you think the resources included in the guidance will assist staff working in health and social care services understand and implement a human rights-based approach to care?
6. What other guides or tools would support the implementation of the guidance?

Appendix E — Public Consultation Feedback Form



Draft Guidance on a Human Rights-Based Approach to Care and Support in Health and Social Care Settings

Public consultation feedback form

5 June 2019

We are holding a public consultation to give people an opportunity to provide feedback on this draft guidance. Your views are very important to us, and we will carefully assess all feedback received and use it to help develop the final guidance. The guidance and a related statement of outcomes document (a summary of the responses) will be published once the guidance has been approved.

Please note: the focus for this consultation is the content and structure of the draft guidance. The final design and layout of the guidance will be developed after the public consultation.

We would like your feedback on each of the sections in the document. There are also some general questions about the overall document.

For each comment you make, it would help us if you provided the section and page number your comment relates to.

We welcome responses to all questions as well as any additional general comments you would like to make.

The closing date for consultation is 5pm on 17 July 2019.

Instructions for submitting feedback

- If you are commenting in a personal capacity, there is no need to provide your name or any other personal information. However, if you would like to be contacted to partake in future focus groups, there is an option to provide your name and contact number.
- If you are commenting on behalf of an organisation, please combine all feedback from your organisation into one submission form. In this case, we will request a name and contact number for a designated representative from your organisation should we need to verify the authenticity of your contribution.
- When completing this form online, please ensure you scroll down the webpage and complete the form in full.
- Please include the page number and section that you are commenting on.
- Do not paste other tables into the boxes already provided — type directly into the box as the box expands.
- Please spell out any abbreviations that you use.

You can email or post a completed form to us. You can also complete and submit your feedback on www.hiqa.ie

Data Protection and Freedom of Information

HIQA will only collect personal information during this consultation for the purposes of verifying your feedback or where you have indicated that you would like to be contacted to partake in future focus groups. If you have any concerns regarding your data, please contact HIQA's Information Governance and Assurance Manager on infogovernance@hiqa.ie. Please note that HIQA is subject to the Freedom of Information (FOI) Act and the statutory Code of Practice in relation to FOI. Following the consultation, we will publish a statement of outcomes document summarising the responses received, which will include the names and types of organisations that submitted feedback to us. For that reason, it would be helpful if you could explain to us if you regard the information you have provided us as being confidential or commercially sensitive.

If we receive a request for disclosure of the information under FOI, we will take full account of your explanation, but we cannot give you an assurance that confidentiality can be maintained in all circumstances.

1. About you

Any information you provide and your feedback form will be held securely and will not be published, subject to legal requirements under Freedom of Information (FOI) legislation or where you are responding on behalf of an organisation, in which case the name and type of organisation will be published in a statement of outcomes document. The feedback received will only be used to help develop the final guidance.

1.1 Please tick as appropriate — are you providing feedback as:

an individual - contact information provided

(If you would like to be contacted to partake in future focus groups, please provide your name and contact number)

an individual - anonymous

on behalf of an organisation:

(For verification purposes, please provide the name of your organisation and a name and landline contact number for a contact person in the organisation.)

1.2 Please tick as appropriate — are you commenting as:

a staff member or other person working in a health or social care service

(Please specify your role)

a person who has used or is currently using a health or social care

service

Other

(Please specify)

2. Your feedback on the draft guidance

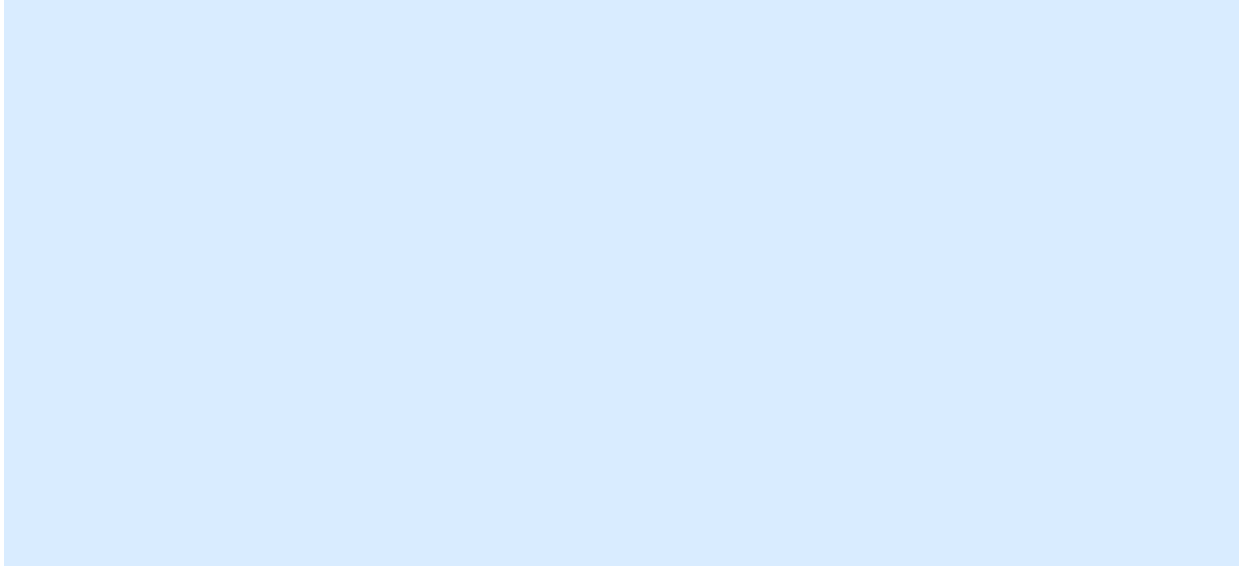
In this section, we would like to find out what you think of the content of the Draft Guidance to Support a Human Rights-Based Approach to Care and Support in Health and Social Care Settings.

Please consider the following questions as part of your review:

- Do you think all important areas have been covered under each principle or are there any areas that should be included or excluded?
- Are the case studies included in each section sufficient to assist staff working in health and social care services understand a human rights-based approach to care and support?

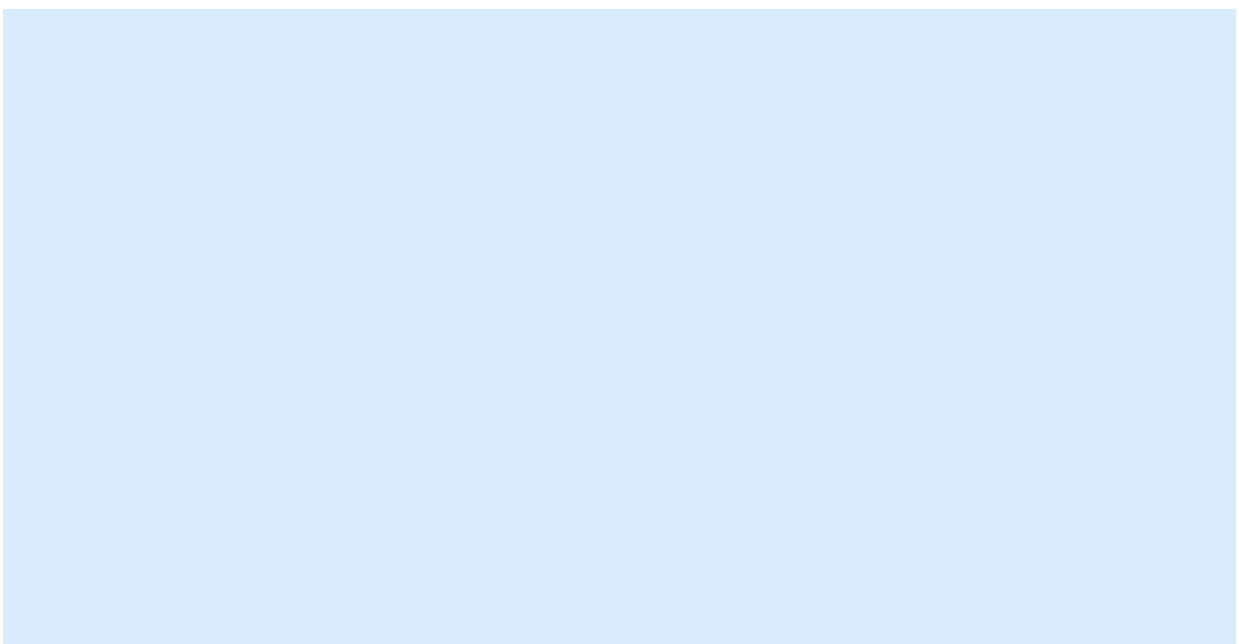
2.1 Please provide your comments on the section 'An overview of human rights'

Please include section and page number (if applicable)



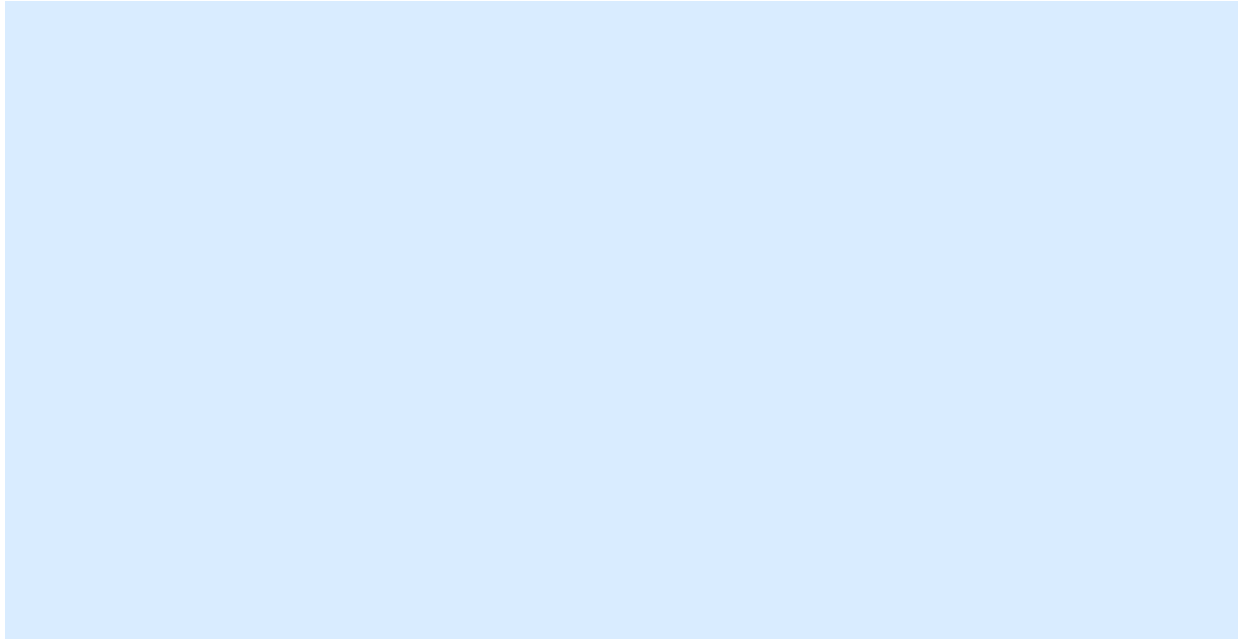
2.2 Please provide your feedback on the FREDA principles (for example, do you think they are relevant and useful for people working in health and social care services?)

Please include the principle, section number, section title and page number you are commenting on



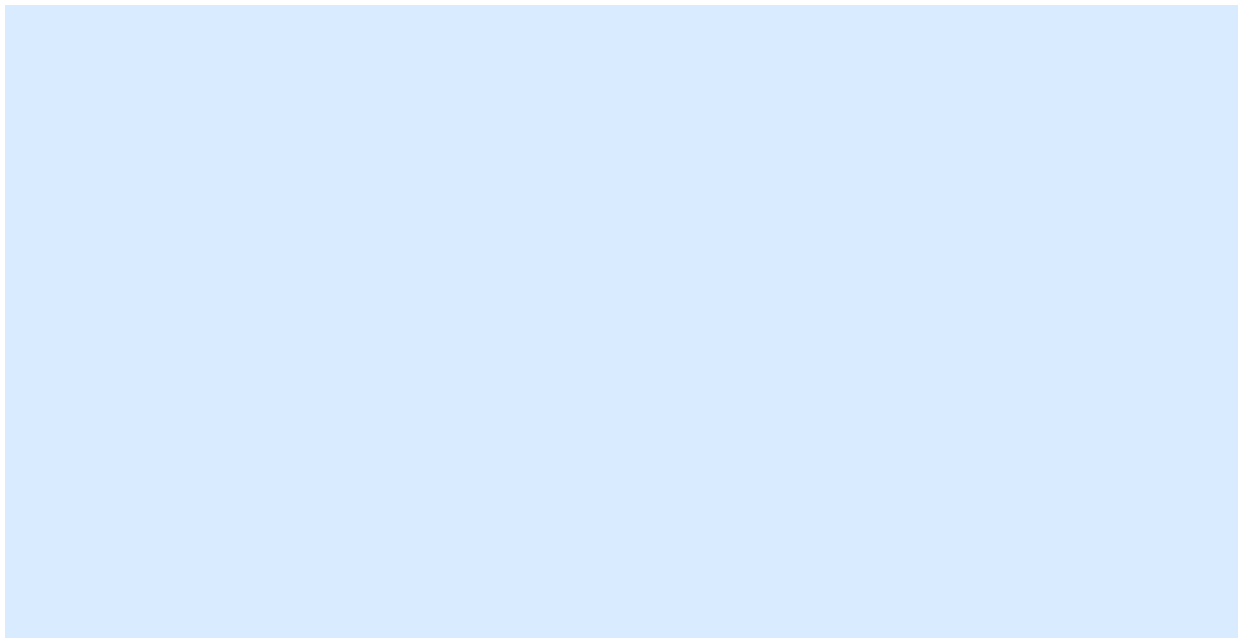
2.3 Do you think the case studies in the document are relevant for people who work in health and social care services? Please explain your answer below.

Please include section and page number (if applicable)



2.4 Do you have suggestions for the type of case studies that could be included?

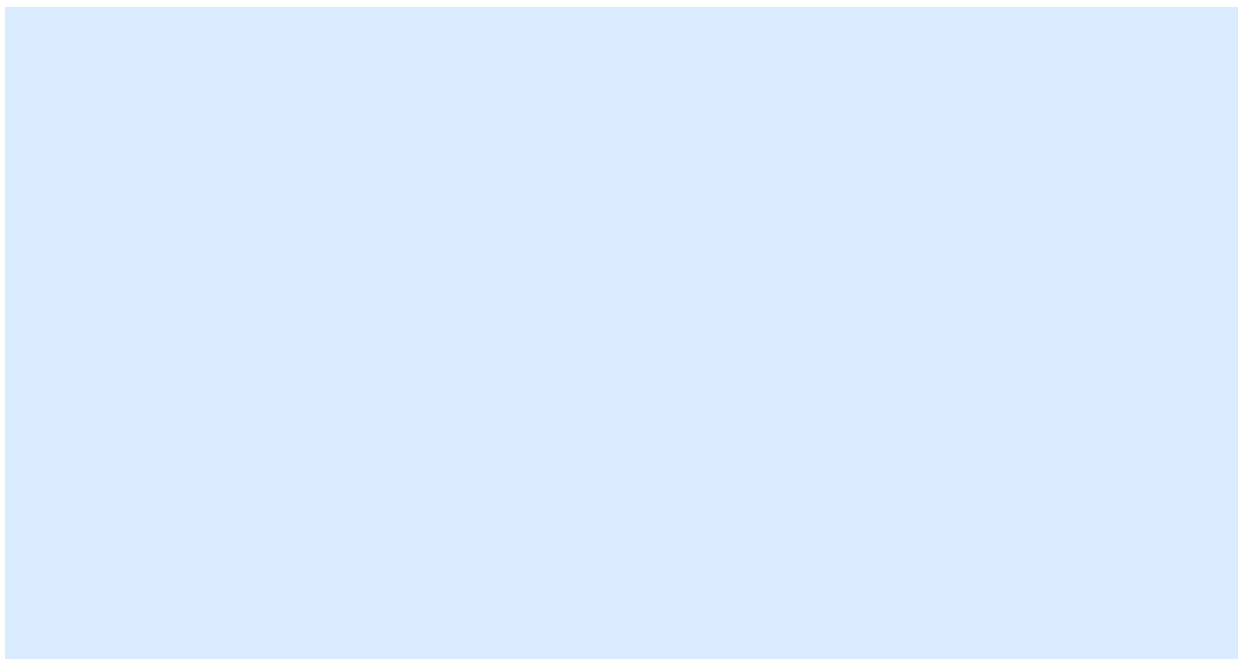
(Please provide below)



2.5 Please provide any comments on the resources provided in the document, stating the resource number



2.6 Are there any other comments or suggestions on the draft guidance that you would like to make?



3. General feedback

3.1: a) Is the language used in the draft guidance clear, easy to follow and easy to understand?

Yes **No**

b) Is the content and structure of the draft guidance clear, easy to follow and easy to understand?

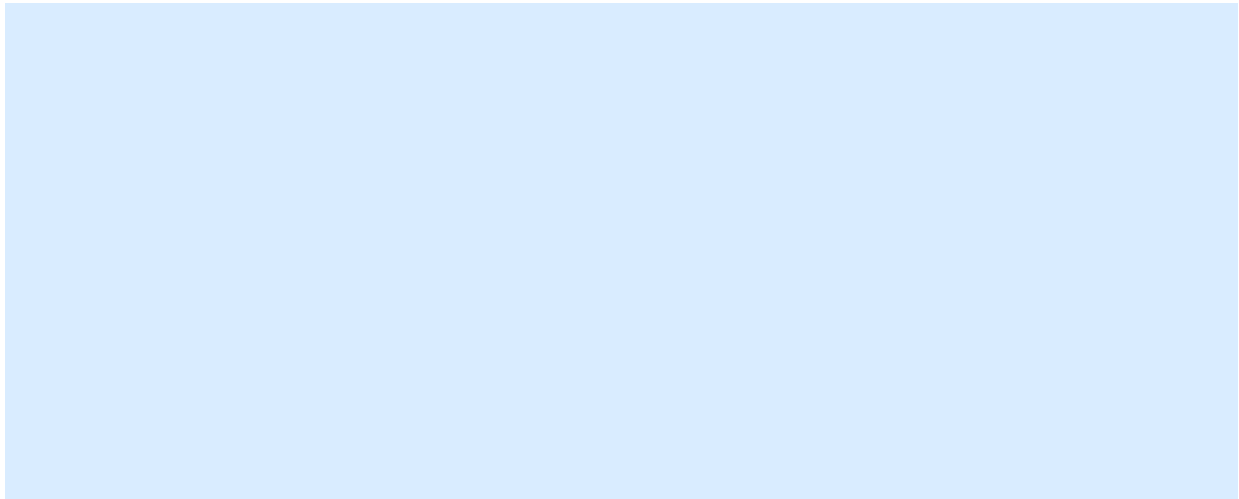
Yes **No**

3.2: Please provide any additional comments on language, content and structure

3.3: Having read the draft guidance, do you have a better understanding of human rights and how they apply to your work?

Yes **No**

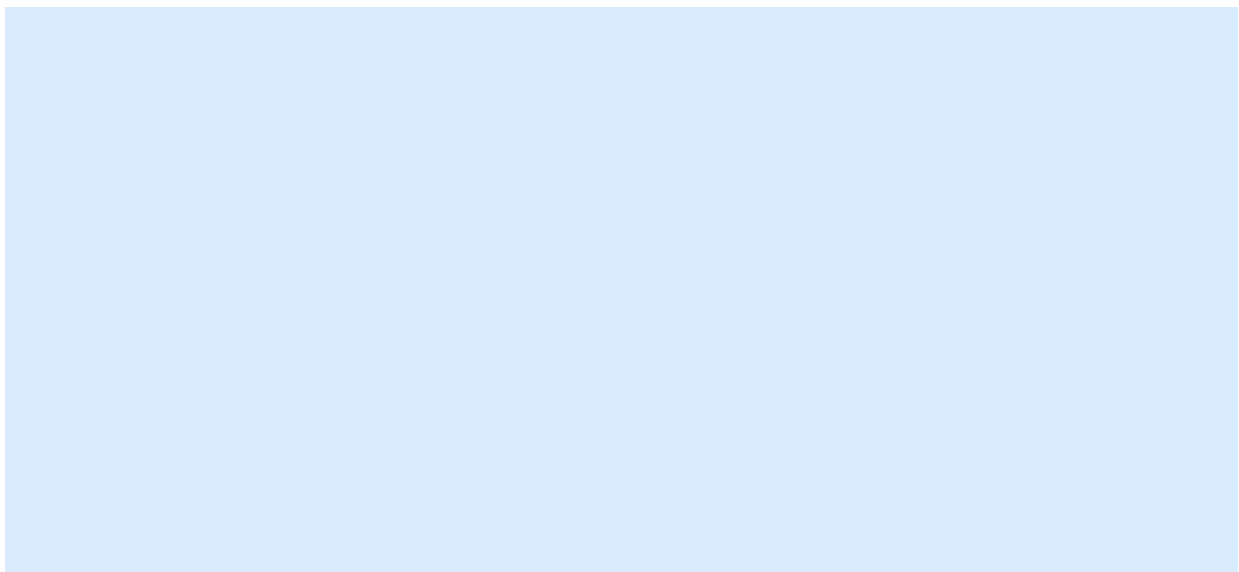
Any additional comments:



3.4: Having read the draft guidance, do you intend to make changes to your work practices?

- Yes** **No**

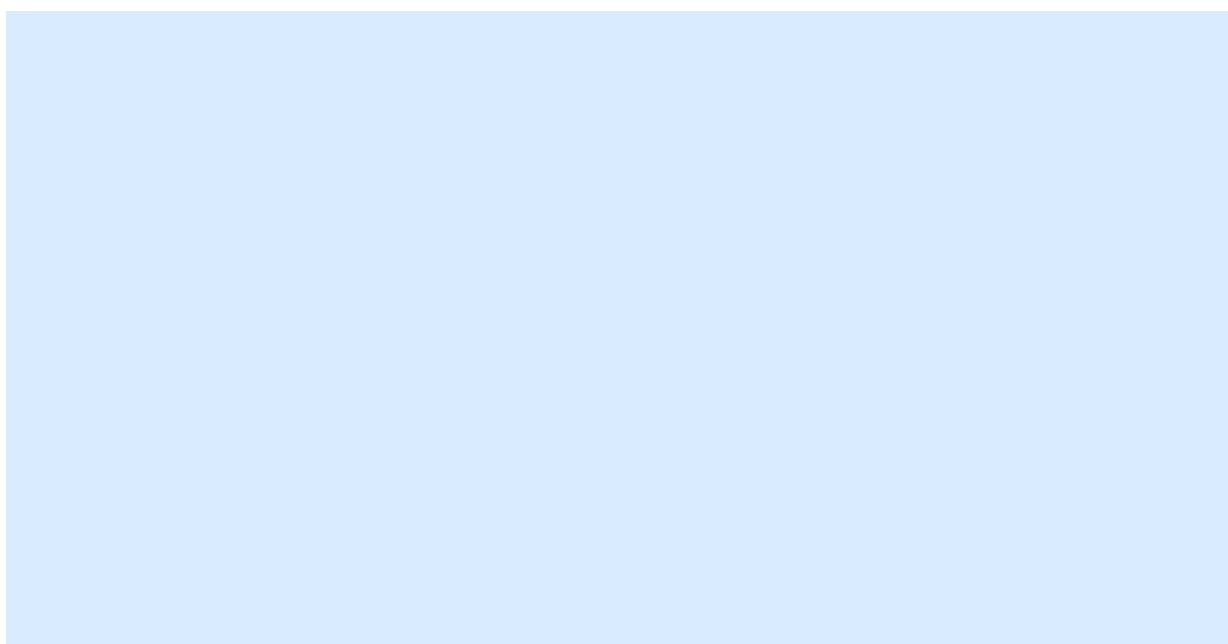
Any additional comments:



3.5: Do you think this guidance will be a useful resource for people working in health and social care services?

- Yes** **No**

Please provide reasons for your answer:



Thank you for taking the time to give us your views on the *Draft Guidance to Support a Human Rights-Based Approach to Care and Support in Health and Social Care Settings.*

Please return your form to us by email or post.



You can download a consultation feedback form at www.hiqa.ie and email the completed form to standards@hiqa.ie



You can print off a consultation feedback form and post the completed form to:

Health Information and Quality Authority
Draft Guidance on a Human Rights-Based Approach to Care and Support in Health and Social Care Settings
Dublin Regional Office
George's Court
George's Lane
Smithfield
Dublin 7
D07 E98Y



If you have any questions on this document, you can contact the standards team by phoning: **(01) 814 7400** or email: **standards@hiqa.ie**

Please ensure that you return your form to us either by email or post by 5pm on 17 July 2019. Unfortunately, it will not be possible to accept late submissions.

Appendix F — Organisations that made submissions to the public consultation

Organisations that responded to the public consultation (June – July 2019):

- Active Retirement
- Age Action
- Age Advocacy
- Beam Services Bagenalstown
- Beech Lodge Care Facility
- Brothers of Charity Services Ireland, Limerick Region & Southern Region
- Callan Institute
- Cappagh National Orthopaedic Hospital
- Centre for Disability Law and Policy, NUI Galway
- Cheshire Ireland
- Chime
- Citizens Information Board
- COPE Galway
- Cowper Care DAC
- Disability Federation of Ireland
- Down Syndrome Ireland
- Droimnin Nursing Home
- Ennis Road Care Facility
- HavenWood Retirement Home
- Hillview Nursing Home
- HSE National Safeguarding
- Inclusion Ireland
- Irish Advocacy Network
- Irish Association of Social Workers
- KARE
- National Adult Literacy Agency
- National Advocacy Service for People with Disabilities (NAS)

- National Disability Authority
- National Federation of Voluntary Service Providers
- Nua Healthcare Services
- Nursing Homes Ireland
- Positive Futures
- Rehab Group
- SCI Special Interest Group
- St Theresa's Nursing Home
- St. Carthage's House
- St. Joseph's Shankill
- Tallaght University Hospital
- The Irish Hospice Foundation
- Tusla
- WALK



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