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## Translating a Human Rights-based Approach into Health and Social Care Practice

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# Translating a Human Rights-based Approach into Health and Social Care Practice

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The aim of this work was to translate the legalistic nature of human rights into a practical way of working for those working across health and social care services in Ireland. In particular, it aimed to identify specific barriers to implementation of a human rights-based approach (HRBA) to care, most notably in terms of gaps in knowledge of frontline staff and to develop practical resources such as guidance to show how they can respect, promote and uphold people's rights. A comprehensive literature review was undertaken and extensive engagement with health and social care stakeholders including, staff, advocates, and adults who use health and social care services was conducted. Stakeholder engagement consisted of public consultations, focus groups, and convening an advisory group. Findings from the literature review and the stakeholder engagement indicate that a lack of understanding regarding how to implement and practically apply a HRBA exists among frontline staff and management in health and social care services. It was identified there was a need to develop guidance to support health and social care staff in understanding a HRBA to care and support and to assist them in the implementation and application of human rights principles in their everyday work.

Keywords: human rights-based approach, human rights, FREDA principles

## Introduction

Human rights are the basic rights and freedoms all people should enjoy and are protected under the Universal Declaration of Human Rights (UDHR) (*The Universal Declaration of Human Rights*, 1948) and in the European Convention on Human Rights (ECHR) (*European Convention on Human Rights Act*, 2003). A human-rights based approach (HRBA) ensures the human rights of people using health and social care services are protected and supported in practice, and embedded in service culture (Curtice & Exworthy, 2010). In health and social care this means treating people fairly, with dignity and respect and ensuring they can participate fully in decisions about their care. A HRBA approach to health and social care involves empowering people to know and claim their rights and involves increasing the

ability and accountability of staff working in health and social care services to respect, protect and fulfil the human rights of people using services.

The Irish Constitution (1937) sets out the fundamental rights of Irish citizens and features human rights which are relevant for health and social care (*Constitution of Ireland*, 1937). Recently in Ireland, with the introduction of national and international human rights legislation, there has been a shift in policy and practice to a focus on human rights, empowerment and choice. This has stemmed, in part, from the ratification of international treaties that have evolved from the UDHR, including the *United Nations Convention on the Rights of Persons with Disabilities* (UNCRPD) 2006, the ECHR and the introduction of the *Assisted Decision-Making (Capacity) Act*, 2015. Respect for human rights is also implicit within the codes of conduct and ethics of health and social care staff (Irish Association of Social Workers, 2009; Medical Council, 2016; Nursing and Midwifery Board of Ireland, 2014).

In Ireland, the Health Information and Quality Authority (HIQA) is a statutory body, established under the Health Act 2007, tasked with driving high-quality and safe care for people using health and social care services (*Health Act*, 2007). One of HIQA's functions is to set national standards for these services and to ensure they are met, through registration and inspection of services. HIQA has developed national standards relevant to those working in health and social care services. These place people using services at the heart of care and support processes and ensure service providers protect them from harm. They promote up-to-date practice, protect human rights, and empower people using services to protect themselves. High-level reference is made to a HRBA in a number of national standards with emphasis placed on protecting and promoting rights and respecting autonomy, privacy, dignity and diversity (HIQA, 2012, 2013, 2016a, 2016b).

Although human rights are enshrined in legislation, set out in codes of professional conduct and in national standards, recent reports suggest there is a lack of knowledge and understanding in their practical application (HIQA, 2017; Mental Health Commission, 2018). Ginsburg and Bäärnhielm (2008) and Jovic et al. (2015) found that a gap in the knowledge of health and social care staff of how to incorporate a HRBA into day-to-day practice exists and there is difficulty in practically applying the legislation as part of everyday care and support. This finding is also evident in inspection reports published by HIQA (HIQA, 2017, 2018a). One of the regulations HIQA inspects against in residential centres for older people and people with disabilities is in relation to residents' rights. A report of inspections undertaken

in 2018 in residential centres for older people reported that, of the 283 centres inspected in 2018, 27% were found not to be compliant with this regulation (HIQA, 2019a).

Human rights can be considered from a number of different perspectives or from a mix of perspectives. This study discusses human rights from a legal perspective and a healthcare perspective. However, it is important to note that complexities can arise when considering human rights from different perspectives. For example, Griffith (2014) found that in health and social care settings, challenges can arise when practitioners need to achieve a balance between upholding the human rights of people using services and maintaining their duty of care to people using services. Young (2009) suggests that a shift away from a paternalistic model of care towards one focused on patient empowerment and autonomy has had implications for health and social care staff. Staff are faced with trying to protect the health and wellbeing of people using services while also promoting their autonomy (Cole, et al., 2014). Baxter and Carr (2007) suggest that this becomes challenging when staff are providing care and support to vulnerable people who may lack capacity to make a particular decision but their human rights still need to be upheld.

Gavrielides (2011) argues that emphasis is placed on the legalistic nature of human rights rather than their underlying values. Furthermore, Curtice and Exworthy (2010) suggest the legalistic nature of human rights has resulted in frontline staff finding it difficult to interpret how their day-to-day work should be informed by a HRBA. It can be useful to think of human rights in the context of principles. The FREDA principles (Fairness, Respect, Equality, Dignity and Equality) represent a non-legalistic approach to human rights for health and social care (Scottish Human Rights Commission, 2018). Curtice and Exworthy (2010) suggest the principles are the basics of good care and form part of what practitioners do on a daily basis. This study aimed to translate the legalistic nature of human rights into a practical way of working for those working across health and social care services in Ireland. In particular, it aimed to identify barriers to implementing a HRBA, most notably in terms of gaps in knowledge of frontline staff and to develop practical guidance to show how they can respect, promote and uphold people's rights.

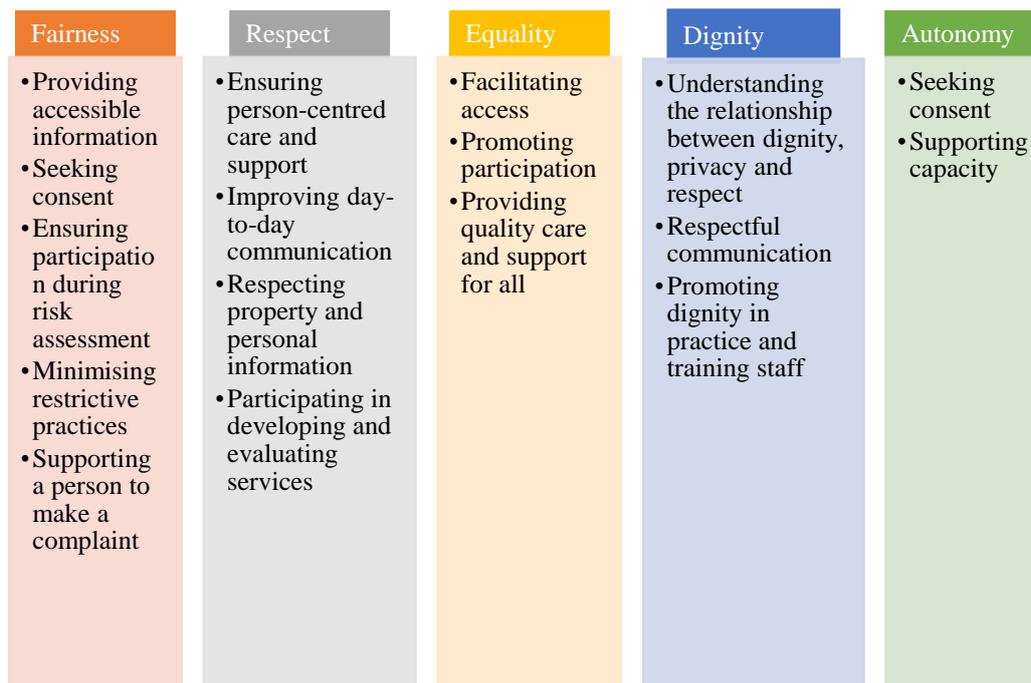
## **Literature Review**

A literature review was conducted to identify characteristics of human rights-based care and support practices for adults in health and social care settings. The review was conducted systematically and complied with HIQA's evidence synthesis process (HIQA, 2018b). Grey

and academic databases were searched (Lenus, Open Grey, ASSIA, CINAHL, Pubmed, PsycINFO, SocINDEX, Social Services Abstract and Social Sciences). A description of the search strategy has been published previously (HIQA, 2019b).

The FREDA principles were identified as themes and were used to structure literature review findings (Figure 1).

**Figure 1: Key themes identified under the FREDA principles**



### *Fairness*

Fairness means ensuring when a decision is made with a person using a service about their care and support, the person is at the centre of the decision-making process. The person's views are sought, listened to and weighed alongside other factors relevant to the decision. If a decision interferes with a person's human rights, this must be legally justified, proportionate and only taken when all other alternatives have been considered (HIQA, 2019b).

### *Providing accessible information*

Health and social care staff can ensure their practices are fair and consistent by providing comprehensive information in an accessible and meaningful format to the person using

services (The Alzheimers Society of Ireland, 2013). This will facilitate them to make independent choices about their care and support. This cannot be addressed without considering the person's preferences for the format and manner in which they receive information, and the need to provide information in ways that are meaningful and accessible to people with intellectual or physical disabilities. Lewkonina (2011) suggests that tools such as leaflets and videos containing clear and simple information are practices that can enhance the accessibility of information in health and social care settings.

### *Seeking consent*

Person-centred decision-making places the individual at the centre of the decision-making process and is considered a key element of fairness. People using services should have their views weighed with the knowledge and experience of staff in relation to decisions about their care. Staff should give effect to the person's will and preferences as far as practicable (Health Service Executive, 2013; Scottish Human Rights Commission, 2016). Staff need to ensure they communicate effectively, the benefits and risks of all proposed and alternative treatment options to people using services (Sakellari, 2003; Szmukler, 2017). An essential element to the consent process is ensuring the person using services has the capacity to make a particular decision. The Health Service Executive (2013) proposes that best practice favours a functional approach to defining whether a person has decision-making capacity.

### *Ensuring participation during risk assessment*

Mersey Care NHS Trust (2008) suggest that for a service to be fair, it is vital for the service to have clear and consistent processes in place regarding risks. Risk assessments should apply explicit criteria and form part of an overall assessment process. Fair processes allow people using services to access information held about them regarding risk. They should also know in advance on what basis this information may be shared with others. (Mersey Care NHS Trust, 2008). For example, decisions relating to risk should consider the person's quality of life, rights and choice.

### *Minimising restrictive practices*

Roberts et al. (2013) suggest that positive risk-management can help build a culture within a service where risk management is openly discussed and proactively managed. Proactive

management with regard to the use of restrictive practices has also been identified by Hall and Duperouzel (2011) as a core component of fairness within health and social care. In order to achieve fairness, the World Health Organisation (2012) has indicated that it is essential staff implement safeguards to ensure restrictive practice is only used when it is in the person's best interests, it is regularly reviewed and removed as soon as possible.

#### *Supporting a person to make a complaint*

Services are required to conduct transparent processes when dealing with concerns regarding professional conduct or performance of health and social care services. Roberts et al., (2013) suggest that the health and social care complaints system can be ineffectual, time-consuming and inaccessible. The main barriers to making a complaint have been identified as a lack of knowledge on how to make a complaint, fear of repercussions, and uncertainty that anything would change as a result (Community Action Network, 2018; Office of the Ombudsman, 2015). It is essential that services create a supportive and transparent environment whereby people are supported in making a complaint without fear of negative consequences.

#### ***Respect***

Respect is the objective, unbiased consideration and regard for the rights, values, beliefs and property of other people. Respect applies to the person as well as their value system (HIQA, 2019b).

#### *Person-centred care and support*

Curtice and Exworthy (2010) suggest that in order to uphold respect, people who use services must be valued as individuals, listened to, and what is important to them must be viewed as important by the service. Upholding respect means considering a person's views, wishes and feelings and ensuring decisions, as much as possible, are aligned with a person's wishes. Literature suggests respect can be promoted by involving people using services in service development, which will provide staff with an opportunity to understand how people perceive they are being treated (Bell et al., 2007; Curtice & Exworthy, 2010). In this approach, people are not treated as passive recipients of goods and services, but as participants in decisions affecting their wellbeing. This shows respect for a person's thoughts and belief systems (Department of Health, 2008).

### *Indicators of respect*

Research has been conducted to assess how respect can be measured in health and social care services. Manthorpe (2009) suggest that common indicators for respect include respectful delivery of care and support, knowledge of and respect for an individual's preferred lifestyle, and respect for a person's property and possessions. This research also suggests people using services should have individualised plans that support achievement of goals and empower them to live their lives according to their wishes. Appropriate communication, non-discrimination, and ensuring the participation of people using services in the development of services can help promote respect in health and social care settings.

### *Equality*

Equality means people having equal opportunities and being treated no less favourably than other people on the grounds set out in legislation. In an Irish context these grounds are age, civil status, disability, family status, gender, membership of the Traveller community, race, colour or nationality, religion or sexual orientation. Within health and social care, equality can also relate to equality of access to and outcomes from care and support.

### *Facilitating access*

Literature indicates that human rights in relation to access to care can be breached on account of the status of a person using services (Age UK 2011; Mathews & Sanz, 2011). Studies have shown that people who have experienced inequality with regard to accessing care and support have attributed access issues to their disability, age or health status (Bollard, 2009; Szmukler, 2017). Health and social care staff have a responsibility to ensure services are accessible and their communication with people is appropriate, respectful and delivered in an accessible and understandable format.

### *Promoting participation*

A lack of promoting opportunities to participate in and contribute to society was reported in the literature (Age UK, 2011; Mathews & Sanz, 2011). Research has focused on the gap between human rights objectives and the actual experiences of people using services. It has been reported that people with intellectual disabilities have experienced wide-ranging rights violations and discrimination, which excludes them from the communities in which they live

(Kogstad, 2009; Sheerin, 2011). This resulted in their experiences of living in their communities being different to that of mainstream society. The research suggests the violations may have been a result of services focusing on treatment and care rather than on supporting people to live independently and participate in society.

#### *Providing quality care and support for all*

Identifying unequal outcomes in care and support is a central aspect of equality (Age UK, 2011; Irish Human Rights and Equality Commission, 2016; Mathews & Sanz, 2011). Health and social care providers should understand the barriers people using services face and directly engage with people to understand their needs and views. The British Institute of Human Rights (2016) suggests that health and social care staff should ensure that prior to making a decision that may restrict a person's right, they should ensure the decision is lawful, legitimate and necessary.

#### *Dignity*

Dignity means treating people with compassion and in a way that values them as humans and supports their self-respect, even if their wishes are unknown at the time (HIQA, 2019b).

#### *The relationship between dignity, privacy and respect*

The Scottish Human Rights Commission (2016) indicates that respect for a person's dignity is an important measure of success for health and social care services. Dignity is central to all human rights and overlaps with the principles of privacy and respect. Jackson and Irwin (2011) indicate that supporting and preserving the dignity of people using services is a fundamental aspect of care and support. When dignity is maintained in health and social care, research indicates that working relationships are improved which facilitates appropriate decision-making. Conversely, research by Martin (2004) suggests that in instances where dignity is not preserved, staff can experience feelings of insecurity, anger, frustration, lack of confidence, reduced motivation, reduced quality of patient care, and decreased satisfaction.

#### *Communicating sensitively*

Jackson and Irwin (2011) identify good communication as a crucial aspect of preserving dignity, and report a positive association between active listening and upholding dignity.

Another study of patient dignity in psychiatric settings found patient's dignity was perceived to be upheld when nurses connected with patients and allowed themselves to be moved by patients' stories (Lindwall et al., 2012). The link between active listening and upholding dignity has also been highlighted in disability settings. For example, Inclusion Ireland (2017) suggest services should treat people with intellectual disabilities with dignity and respect and interactions should be accessible, friendly and respectful and involve listening.

#### *Promoting dignity in practice and training staff*

Baer et al. (2016) propose that adequately skilled, competent and empathetic staff are core components of a good-quality health service. Similarly, Martin (2004) found that an increased focus on ethics in learning and training environments and combining ethical values and professional subjects are essential for training health and social care practitioners in the principle of dignity. Jackson and Irwin (2011) suggest that patient surveys are a useful way of measuring the degree to which people using services feel they were treated with dignity in health or social care settings.

#### *Autonomy*

Autonomy is the ability of a person to direct how they live on a daily basis according to personal values, beliefs and preferences. In health and social care settings, autonomy involves the person using a service making informed decisions about their care, support or treatment (HIQA, 2019b).

#### *Seeking consent*

In health and social care, autonomy is often related to a person's ability to provide consent. People have the right to obtain information about their healthcare and they also have the right to accept or reject any options for care and treatment. Cole et al., (2014) suggest this can conflict with a paternalistic approach to patient autonomy, for example, making decisions in the 'best interest of the patient' can result in the person using services being denied full autonomy to express their will and preferences. The 'best interests' approach is inherently paternalistic and infringes on a person's right to autonomy and to fully express their will, decisions and actions. Under this approach, if a person is deemed not to have capacity, the 'best interests' of the person are determined by the healthcare provider (Keeling, 2017; Safeguarding Ireland, 2018).

*Supporting capacity and responding accordingly*

There is consensus in the literature that health and social care services need to build supportive environments for people using services in order to empower them to develop their capacity. This involves encouraging people using services to be involved in service development, which has been reported to result in a more inclusive, autonomy-supportive approach to risk management (Hall & Duperouzel, 2011; Yamin, 2008). Collaboration between health and social care staff and people using services can help build mutual respect between the two groups and foster future engagement.

**Methods**

Extensive engagement with health and social care staff, advocates and adults who use health and social care services was undertaken to determine areas of practice that require a human rights focus, to identify barriers to implementation of a HRBA, and to support development of resources to address these barriers. The views of people with experience of health and social care services were sought through consultation and focus groups (HIQA, 2019c).

*Scoping consultation*

A public scoping consultation was held to inform the development of guidance to support a HRBA in health and social care services. An online survey was disseminated through the HIQA website. The four-week consultation took place in October 2018. The purpose was to consult with people with experience of health and social care service, seeking high-level responses to inform guidance development. Table 1 outlines the scoping consultation questions.

**Table 1: Scoping Consultation Questions**

1	What are the key areas that the guidance should address?
2	What are the key sources of information that we should review to inform the development of the guidance?
3	What organisations or individual should we engage with when developing the guidance?

*Focus groups*

Six focus groups were held with 39 participants in January 2019. Participants included frontline staff and management, people using services and advocates from health and social care services including, disability, primary care, older persons, advocacy, mental health and substance misuse services (HIQA, 2019c). Scoping consultation respondents were asked if they would like to be involved in focus groups related to the development of guidance on a HRBA. Respondents who expressed interest were subsequently invited to participate. Table 2 outlines focus group questions.

**Table 2: Focus Group Questions**

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?

Two members of HIQA's Project Team attended each focus group, one member facilitated and one took notes. Informed written consent was obtained from participants. It was outlined the notes would be treated confidentially with points summarised and not attributed to individuals and that anonymised information would be used to inform the development of the guidance and for research purposes. Table 3 details the number of participants who participated in the stakeholder engagement process.

**Table 3: Number of participants/responses to stakeholder engagement**

<b>Stakeholder Engagement</b>	<b>Responses / Participants</b>
Scoping Consultation	51 responses
Focus Groups, January 2019	39 participants
Focus Groups, June 2019	20 participants
Public Consultation	75 responses

### *Analysis*

Two project team members coded focus group notes and developed a coding framework. A deductive approach was taken to facilitate the collation of themes under the FREDAs principles. The researchers redefined the framework by discussing convergence and divergence of themes and the main thematic categories were formed. Consensus on themes was reached through discussion and there was a high level of intercoder reliability. Where agreement was not reached, a third researcher resolved differences. A guidance document was drafted using the FREDAs principles to address the knowledge gap in understanding what a HRBA is. The guidance is intended for all staff working in health and social care services with the purpose of assisting them to uphold human rights in their everyday practice. To ensure the guidance was practical and applicable across sectors, the draft guidance was made available for public consultation over a six-week period in June 2019. A total of 75 responses were received and reviewed by the Project Team. Subsequent changes to the draft guidance were agreed between the team and the final version was approved by the Director.

Three additional focus groups were held comprising of 20 participants. In advance of the focus groups, 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. All feedback was reviewed and the guidance document was revised accordingly (HIQA, 2019c).

## **Results**

### ***Scoping Consultation***

The findings indicate that health and social care staff felt they require training to enhance their understanding of how to practically apply a HRBA to care and support in their work. Specifically, there was a desire among staff for issues surrounding consent and capacity to be addressed. Support was sought regarding the role of independent advocates, family members and organisations in decision-making, particularly when the person using services does not have full capacity to make decisions independently. Over 300 information sources (legislation, policies, standards, books, journal articles and websites) were suggested for review to inform the development of resources. All suggested sources were retrieved and compared with sources identified during the evidence synthesis process and any new and relevant sources were added to the evidence base. Respondents identified organisations and individuals that should be engaged with during guidance development. Suggestions were

compared to the project's stakeholder engagement plan to ensure there was sufficient representation from key groups and organisations.

Findings from the scoping consultation addressed two aims of this study which were to identify barriers to implementing a HRBA to care and support and to identify resources to support health and social care staff in implementing a HRBA. The literature review and focus groups addressed another aim, which was to translate the legalistic nature of human rights into a practical way of working for health and social care staff.

## **Focus Groups**

Each of the identified themes from the focus groups are discussed under the FREDA principles and verbatim examples relating to each theme are provided.

### *Fairness*

Participants emphasised the importance of people using services having a choice on how they would like to receive information in an accessible format. They noted the importance of providing information on all treatment options to the person, including information on the risks associated with each option and options that the service itself cannot provide.

Other countries are better at providing information around choice and care and they lay out all options and risks even if they can't facilitate all of the options. More training is needed on this.

Staff need to answer the question 'have I given the person all the information they require and in an accessible way they can understand?'

Participants acknowledged that obtaining consent can be time and resource intensive, but ultimately a worthwhile and important process. Obtaining consent in an acute healthcare setting was described as a rushed exercise where the main objective is to get a signature from the person to consent to treatment or intervention. The need for better tools and guidance around consent for adults with intellectual disabilities was highlighted. It was felt that the diverse needs of a person should be respected in daily practices and when making a decision.

They should be treated as having the same capacity as everyone else and should be supported to communicate and express their consent using appropriate methods and tools.

Informed consent is about looking at the risks and looking at the benefit, it should be done alongside the person using the service to facilitate shared decision-making.

Participants also felt a lack of awareness of human rights can lead to inappropriate use of restrictive practices. For example, in disability services, blanket policies often exist without any awareness of how they may infringe on the rights of people using services.

Sometimes there isn't an awareness of what human rights are. For example, locking doors for protection but not being aware this could be a human rights violation.

### ***Respect***

Participants discussed the importance of person-centred care, respecting a person's right to make a choice and involving people using services in decisions around their own care and support. They emphasised the importance of communication by taking the time to explain care plans or treatment options clearly and discuss the person's wishes or needs.

Staff who treat patients with respect are friendly, supportive and open and start with the question 'what would you like' and then negotiate what is possible from there.

As health and social care practitioners, it is important to take the time to engage with people using services by asking a person what their wishes are.

Participants noted that asking what a person's wishes are can be met with a fear of not being able to deliver what the person requests. However, there was consensus that it is important to have the conversation with the person. It was felt there is a need to recognise the evolving nature of a person's wishes and their care plan should reflect their up-to-date will and preferences. Communication was considered integral to a person's ability to express their rights and participants noted it was essential staff use a range of methods to understand what the person is trying to express.

With person-centred care, services should ask people what they expect of that service.

Asking what a person's wishes are can often be met with a fear of not being able to deliver what a person requests but it is still important to have the conversation in an open way.

Participants reported that facilitating relationships is often avoided in care settings as it is seen as a difficult topic to address. It was felt there are inconsistent attitudes among health and social care staff 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.

Relationships and sexuality can end up being avoided in care as they are difficult and can't be talked about because there are no procedures.

### *Equality*

Participants noted that for people not using services, day-to-day rights are upheld without having to be stated, and this should be the same for people using services. It was suggested it would be useful to ask staff to think about decisions they make and consider what it would be like if someone else was making these decisions for them. Participants emphasised the importance of health and social care services seeing people as people regardless of their background while also acknowledging the diverse needs of people using services and not treating everyone the same.

Services must always see people as people, regardless of their background.

People using services should be viewed as equals to everyone else and be seen and treated as having the same rights as everyone else.

Participants highlighted that people who are non-verbal should be treated as having the same capacity as others. It was noted each stage of care should be explained to them using appropriate methods and tools, to enable them to express their wishes for their care. Participants discussed how a HRBA includes a person being enabled to achieve their role in society and felt it was vital a person using a service is facilitated to achieve a quality of life that is meaningful to them.

Even if a person is non-verbal, they should be treated as having the same capacity as everyone else and be supported to communicate their wishes and to be involved in decisions affecting them.

### ***Dignity***

Participants felt that understanding the relationship between dignity, privacy and respect is an integral aspect of providing quality care and support. It was noted that there is a tendency for people using services to in effect hand over their rights to healthcare providers, particularly in medical settings.

Doctors have complete control over you, when you go to the hospital you almost feel like you have to genuflect.

The diverse needs of a person using services must be respected in daily practices and when making a decision.

Participants discussed examples of dignity being infringed upon in different 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 emergency departments. Participants emphasised that the dignity and personal integrity of people using services should always be respected. They noted that a HRBA should ensure a respectful relationship is maintained between practitioners and people using services.

Dignity and personal integrity should always be respected, for example older people should not be treated like children.

The impact of limited resources on the ability of staff to meet the basic needs of people using services was also discussed. Participants felt that providing supports to staff and to people using services, to support their wellbeing is crucial in ensuring a HRBA is applied.

There is a huge need for more training and understanding of a human rights approach in services but frontline staff are time limited and bombarded with policies, guidance needs to be supplemented with training tools.

### ***Autonomy***

Participants highlighted 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 the decision in the future. Participants felt 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.

A person's capacity to make a decision can fluctuate and a person who may not be able to make a decision about something today, may have capacity in the future and should be repeatedly asked.

Participants emphasised that people using services should be supported to have control in their lives. They noted services can be risk averse and highlighted positive risk-taking may put staff in a difficult position as they may be in breach of a service policy. They noted it can be difficult for staff to stand by while the person using the service makes 'bad' decisions. 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.

Services can be risk averse in order to protect themselves and can often act based on what is considered best interests rather than considering a person's will and preference and actually take positive risks.

Participants discussed the difficulties that staff can experience when working with family members and parents of people over 18 years, who feel they have control over the care of the person using services. Participants noted 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.

Families can sometimes have a sense of control over a person accessing services and are not aware that their adult children have their own rights to make decisions about their care.

## **Discussion**

This study aimed to translate the legalistic nature of human rights into a practical way of working for those working across health and social care services in Ireland. The study also sought to establish whether there was a need to develop resources to support implementation of a HRBA across health and social care services. Congruence exists among findings from the literature review and stakeholder engagement.

Findings suggest that a lack of understanding regarding how to implement and practically apply a HRBA exists among health and social care staff. Findings also indicate there was a need to develop guidance to support staff in understanding a HRBA, and to support them in implementing and applying human rights principles in their everyday work in the areas of person-centred care, good communication, autonomous decision-making and positive risk-taking. These findings are reflective of literature in this area which suggests health and social care staff have difficulty in understanding and practically applying a HRBA as part of their everyday work (Ginsburg & Bäärnhielm, 2008; Jovic Vranes et al., 2015; HIQA, 2017; HIQA, 2018a).

Person-centred care is at the core of a HRBA to care and support. To ensure health and social care staff are placing people who use services at the centre of service development and provision, staff need support with regard to communication. The focus group findings indicate that effective communication between services and the people who use them can help promote autonomous decision-making. Furthermore, findings suggest that good communication can help foster a sense of empowerment where people participate in their care, support and treatment plans. This finding is also reflected in research with good communication identified as a clear indicator of respect and as an integral aspect of upholding the dignity of a person using services (Jackson & Irwin, 2011; Manthorpe, 2009).

Staff need to provide people using services with adequate and accessible information regarding their health and personal status. Similarly, it is vital that services ensure disclosure of personal information respects the right of the person using services to a private life. The focus group findings highlight that staff need to be supported to provide individualised care, which is central to a HRBA. This finding corresponds with research by Manthorpe (2009), where it is indicated that individualised care can empower people using services to live their lives according to their wishes. An individualised approach to care and support will ensure that services provide additional supports if people have specific needs. In addition, the findings indicate that transparency is essential if services are to ensure that decision-making processes are fair and consistent. This relates to the process of obtaining informed consent. Services should always presume an individual's capacity until assessed otherwise and

regularly review capacity as it can fluctuate. This is consistent with literature that suggests health and social care services should build autonomy-supportive environments to empower people using services to develop their capacity (Hall & Duperouzel, 2011; Yamin, 2008).

Similar to findings by Roberts et al. (2013) and the World Health Organisation (2012), focus group findings suggest that an important part of a HRBA is ensuring that restrictive practices are only used after exploring all other options, are proportionate to the behaviour they are being used to restrict and are applied for the shortest possible time. Furthermore the focus groups highlighted that health and social care staff can encounter complex situations in practice. For example, in situations where human rights are competing, staff need to consider the applicability and weighting of each right within that situation and their duty of care to ensure safety and fairness for all people using services. This finding is reinforced by studies conducted by Young (2009) and Cole et al. (2014) which indicate that staff are often faced with the challenge of trying to protect the health and wellbeing of people using services while also simultaneously promoting their autonomy.

The focus groups also indicated that there remains a lack of awareness and understanding among health and social care staff of what human rights are and how they can be infringed upon. This finding is supported by literature which indicates that despite human rights being enshrined in law and featuring in a number of national standards, there remains limited understanding of the practical application of human rights among health and social care staff (Ginsburg & Bäärnhielm, 2008; HIQA, 2017; Jovic Vranes et al., 2015; Mental Health Commission, 2018). This may be attributable to the paternalistic approach to care and support that continues to underpin delivery of some services. The findings outline the need for an organisation-wide approach to be taken to ensure that human rights are embedded in service provision. To facilitate staff to uphold their legislative requirements and also their professional obligations, human rights should be ingrained into organisational culture.

Gavrielides (2011) and Curtice and Exworthy (2010) suggest that the focus on the legalistic nature of human rights has contributed to the difficulty in understanding of how to implement a HRBA human rights among health and social care workers. The focus group findings also emphasised this difficulty in understanding how to implement a HRBA and highlighted the need to educate, train and support staff on how to embed this approach into their everyday work. The findings suggest that guidance on a HRBA should be presented in a format that is practical and applicable across a range of health and social care services and considers the complexity of different situations staff can encounter. For example, case studies

can provide context by illustrating what human rights principles look like in practice in different health and social care settings.

The findings also point to the need to develop additional resources to support staff in the understanding and practical implementation of human rights-based care guidance in the service in which they work in. Specifically, focus group findings revealed that to improve understanding of the nomenclature of human rights, staff require a resource that concisely outlines the legal framework underpinning a HRBA. Findings also highlight that staff need resources to support them when they are faced with making decisions in complex situations. Decision-making flow charts were identified as potential resources to support staff in such instances.

In addition to the HRBA guidance document, the Project Team has developed a number of resources to help health and social care services to apply a HRBA to their everyday work. These resources are available to download [here](#) on the HIQA website. These resources have been widely disseminated to staff across health and social care services and include:

- A legal framework document outlining key national and international legislation underpinning a HRBA to care and support.
- Decision-making flow charts which are helpful tools for staff when making decisions in relation to a person's care or when faced with a decision that may restrict the rights of a person using a service.
- A series of e-learning modules to facilitate translation of the guidance into concise key messages.

The key strength of this study lies within the extensive stakeholder engagement undertaken. The lived experiences of frontline staff and management have informed the guidance, creating a practical, accessible resource that is applicable and implementable across different health and social care settings. Staff engagement has also informed the development of resources to support the practical implementation of the guidance. Implementation of the guidance on a HRBA will help to deliver safer, better healthcare for adults using health and social care services in Ireland.

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