



# Guidance on a Human Rights-based Approach in Health and Social Care Services



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## About this guidance

**The purpose of this guidance is to promote a human rights-based approach to care and support for adults in health and social care services.**



Care and support refers to the help some adults need in order to live the best life they can, despite any illness or disability they might have. A human rights-based approach to care and support seeks to ensure that the human rights of people using services are protected, promoted and supported by staff and services. The attitudes of staff and the language they use when working with people who use the service they work in are crucial to implementing this kind of approach. By using a human rights-based approach, service providers will improve the quality of care and support, quality of life, and safety of people who use health and social care services.

A number of national standards developed by the Health Information and Quality Authority (HIQA) make high-level reference to a human rights-based approach to care and support, with emphasis placed on protecting and promoting people's rights and respecting their autonomy, privacy, dignity, values, preferences and diversity. Reports from the State regulators (HIQA and the Mental Health Commission) have identified that health and social care practitioners and organisations can find it difficult to translate human rights principles into day-to-day practice and service delivery. This guidance is designed to support staff and organisations in understanding a human rights-based approach to care and support, and implementing the principles of human rights in their work.

This guidance has been informed by a thorough review of evidence and extensive engagement with stakeholders. It is written primarily for all staff working in health and social care services, but will also be useful for people using services, their families, carers, friends and advocates.

We recognise that health and social care staff encounter complex situations in practice, where many factors need to be considered; for example an individual's will and preferences and their right to autonomy versus the risk of harm from a particular decision. In some situations there may be competing human rights, and 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 guidance is intended for all health and social care services, to assist staff and organisations to uphold human rights in their practice. A human rights-based approach is an important pillar of all health and social care, which should run in parallel with other statutory and regulatory frameworks that staff are required to follow. The guidance will also support staff and organisations to comply with their Public Sector Equality and Human Rights Duty in respect of Section 42 of the Irish Human Rights and Equality Commission Act 2014.<sup>1</sup>

<sup>1</sup> *The Public Sector Equality and Human Rights Duty places a statutory obligation on public bodies to eliminate discrimination, promote equality of opportunity and protect the human rights of both those they provide services to and staff when carrying out their daily work.*

Resources are included at the end of this document to provide additional support to staff and organisations in understanding and upholding the human rights of people using services:

**Resource 1** provides a description of key human rights that are relevant to health and social care services.

**Resource 2** provides a decision-making aid that uses a human rights-based approach.

**Resource 3** provides useful contacts and links for staff with further information in relation to human rights.



## An overview of human rights

### 1. What are human rights?

Human rights are the basic rights and freedoms that all people should enjoy; including people using services and staff. Human rights are about people being treated with fairness, respect, equality and dignity; having a say over their lives and participating as fully as possible in decisions about their care and support. There is a duty on the State and on health and social care providers to uphold the human rights of people using services and staff.

### 2. Who has human rights?

We are all born with human rights regardless of who we are, where we are from or any other status or characteristics. Although our ability to exercise our rights can sometimes be limited or restricted when the law allows, our rights cannot be taken away from us.

### 3. Why are human rights relevant to your work?

In recent years there has been an increasing focus on human rights, autonomous decision-making, empowerment and choice in health and social care policy and practice. This has highlighted the importance of moving away from a paternalistic approach to care and support towards embedding human rights into service provision and organisational culture. This section sets out some of the main reasons why a human rights-based approach is important to your work in a health and or social care setting.

## It supports you to provide person-centred care and support

Implementing a human rights-based approach will help to support you and your team in delivering person-centred care and support. Person-centred care and support places individuals using services, and their rights, at the centre of all that the service does. Human rights are therefore not 'new' or extra to your work in health and social care services.

Using a human rights-based approach will help you and your team to make decisions in relation to areas of care and support such as staffing levels, provision of treatment, physical restraint, personal care, end-of-life decisions, privacy of personal information, and decisions which affect the day-to-day lives of people who use the service you work in. Human rights should not be viewed in any way as a risk, threat or burden to the provision of care and support. A human-rights based approach will support you and your team to work in partnership with all parties involved in a person's care and support. Upholding human rights can also support you in building relationships with the people who use the services you work in.

## It is your professional obligation

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 for older people's, disability and maternity services, and adult safeguarding. Respect for human rights is also implicit within the codes and guides of conduct and ethics of different health and social care staff including doctors, social workers, nurses, social care workers and allied health professionals. A human rights-based approach ensures your ability to protect the human rights of people using the service you work in. It also promotes professional accountability within the service. If you observe a human rights violation, you have an obligation to report this.

## It is the law

A human rights-based approach to care and support is underpinned by a legal framework and human rights treaties which states have agreed to uphold. This legal framework places a responsibility on health and social care providers at an organisational and individual practitioner level to uphold the human rights of people using their services.

Legal sources of human rights and equality obligations are found in:

- the Irish Constitution 1937
- the European Convention on Human Rights Act 2003
- the Charter of Fundamental Rights of the European Union 2000
- the Equal Status Acts 2000-2015
- the Irish Human Rights and Equality Commission Act 2014.

Importantly, there have also been recent changes to Irish law which relate to a human rights-based approach to care and support, including:

- the ratification of international treaties that have evolved from the Universal Declaration of Human Rights, including the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) 2006, which was ratified in Ireland in 2018
- the introduction of the Assisted Decision-Making (Capacity) Act 2015.

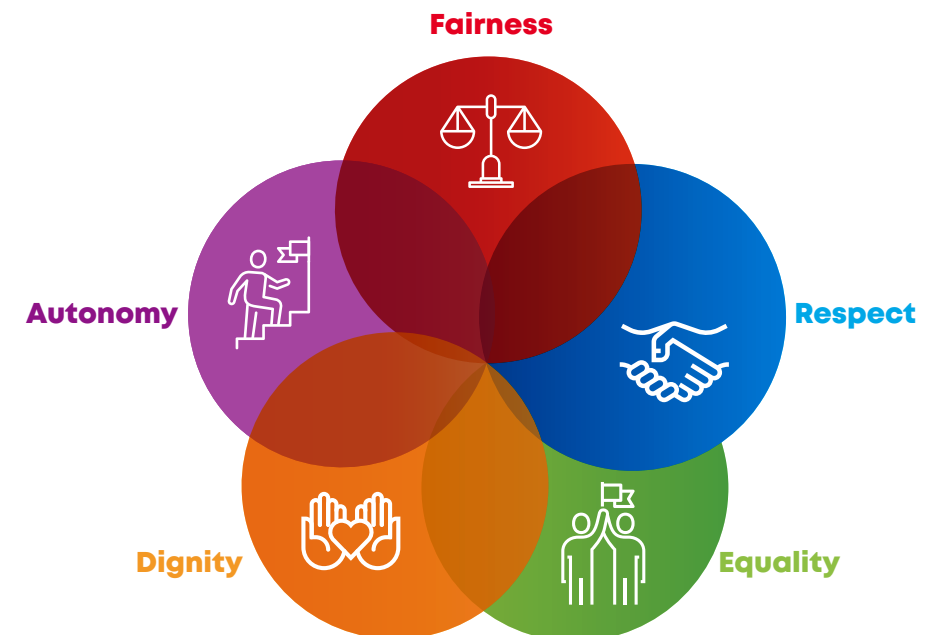
**Resource 1** at the back of this guidance describes the key human rights set out in the European Convention on Human Rights Act 2003 and the United Nations Convention on the Rights of Persons with Disabilities 2006. This document focuses on these two conventions as they are the most often cited and applicable to health and social care services. However, Ireland is a signatory to a number of international human rights treaties, which are all of importance in international human rights law. See **Resource 1** for a link to additional resources on these treaties.



## The FREDA principles – Human rights in practice

Although human rights exist in law, it can be useful to think of them in your day-to-day work in the context of principles. Based on our review of the literature on human rights-based approaches to care, we have used the FREDA principles<sup>2</sup> for the purpose of this guidance, as FREDA is an internationally recognised framework through which human rights can be considered.

These five principles are:



<sup>2</sup> The FREDA principles are outlined in Curtice M, Exworthy T. FREDA: a human rights-based approach to healthcare. *The Psychiatrist*. 2010;34(150-156).

The FREDA principles are the basics of good care and form part of what health and social care practitioners already do on a daily basis. While it is useful to understand and consider each principle individually (as demonstrated in this guidance), it is important to recognise that the five principles are interdependent and often overlap. Therefore examples presented under one principle may also be relevant to other principles. Where this is the case, examples are provided in the context of the relevant principles.

Under each FREDA principle you will find:

- a brief explanation of the principle
- the article(s) from the European Convention on Human Rights Act 2003 and the United Nations Convention on the Rights of Persons with Disabilities 2006 (ratified in 2018) most relevant to that principle
- examples of how you can support and promote the principle in your work
- short case studies of the principle in practice.

The examples of supporting and promoting the principles in your work can also help you reflect on whether or not you are upholding a person's human rights in your day-to-day work.

The case studies aim to provide context by showing you what the principles look like in practice in a health and social care setting. In addition to the short case studies under each principle, there are three extended case studies following the description of the five FREDA principles that illustrate situations where all five principles are applied.

The resources at the end of this booklet are provided as tools to help you understand human rights, how a human rights-based approach can support you to make decisions in your work and who you can contact if you need further information or have concerns about a person using the service you work in.

# T



## 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. The person's views are sought, listened to and weighed alongside other factors relevant to the decision. It is important that decisions are made in a way that is clear and fair, to allow others to know how they might be treated in similar circumstances. 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.

In a health or social care setting, fairness can relate to decisions being made about a person's care and treatment. It can also relate to the process of raising and resolving concerns or complaints, or conducting a risk assessment. Fairness is linked with the core values of equality and autonomy, and with ensuring that the decision-making process is just, free from discrimination and that the person is at the centre of the decision-making process.

### How this principle links to legislation

| European Convention on Human Rights: | United Nations Convention on the Rights of Persons with Disabilities: |
|--------------------------------------|---|
| Article 3                            | Article 5   |
| Article 5                            | Article 12  |
| Article 6                            | Article 13  |
| Article 8                            | Article 21  |
| Article 10                           |   |
| Article 14                           |   |







## 1.1 How can I uphold fairness in my day-to-day work?<sup>3</sup>

### Providing relevant information

- I recognise that people who use the service I work in have the right to receive information in a format and medium appropriate to their communication needs and preferences.
- I recognise that people who use the service have the right to receive information about their own needs, condition, treatment and care provider in a format they can understand and in a timely manner. They also have the right to decide how much information, if any, they wish to receive.
- I recognise that people who use the service may need assistance and support to access information and to communicate their will and preferences<sup>4</sup> through a variety of mediums.
- I provide people with accessible and tailored information on their treatment options, care providers and condition so that they can make independent and informed choices.
- I provide people with information on their human rights and I encourage them to fulfil their rights.

<sup>3</sup> This is not an exhaustive list but provides an indication of how fairness can be supported and promoted.

<sup>4</sup> A person's 'will and preferences' are their wishes, views, beliefs and values.

### Seeking consent

- When seeking consent, I ensure that both I and the person I am seeking consent from are actively involved in this process. I fully explain the risks and benefits of proposed and alternative options in a format they can understand. I encourage the person to ask questions and I check their understanding throughout this process.<sup>5</sup>
- During this process, I ensure that the person knows they have a choice and they can give or withhold their consent freely and without pressure.
- Where decision-making with a person is no longer possible, I consult with the relevant decision supporter under the Assisted Decision-Making (Capacity) Act 2015. If there is no such decision supporter,<sup>6</sup> I may consult the person's family, friends or independent advocate and consider any written documentation or any other record (for example, an advance healthcare directive)<sup>7</sup> to discover the person's past and present will and preferences.

<sup>5</sup> In all cases, 'seeking consent' refers to the granting of permission or agreement for an intervention, receipt or use of a service, or participation in research following a process of communication in which the person using the service has received sufficient information to enable them to understand the nature, potential risks and benefits of the proposed intervention or service.

<sup>6</sup> A decision supporter is a person with legal authority to make personal welfare decisions under a decision-making support arrangement under the Assisted Decision-Making (Capacity) Act 2015.

<sup>7</sup> An advance healthcare directive is an advance expression made by a person with capacity in accordance with the requirements of the Assisted Decision-Making (Capacity) Act 2015 of the person's will and preferences concerning healthcare treatment decisions that may arise if she or he subsequently lacks capacity.



## Facilitating access to and protecting personal information

- I facilitate people to access information about their care and support.
- I facilitate people to access their own personal information.
- I adhere to the person's wishes in relation to what I tell their family.
- I recognise that all medical records and other information recorded about a person are confidential, and I ensure that any potential disclosure I make of this information respects their right to a private life and is in line with legislation.
- I always seek a person's consent before sharing their personal information. I tell the person whose information I am sharing why I am sharing it and who I will share it with. I only share the person's personal information without their consent when I am concerned about the safety of any person and where it is in line with legislation to do so.

## Ensuring participation during risk assessment<sup>8</sup>

- I ensure that when a risk assessment is necessary that there are clear and consistent processes in place and that this assessment is carried out in consultation with the person, taking their views into account.

<sup>8</sup> Risk assessment is defined by the Health Service Executive (HSE) as the overall process of risk identification, risk analysis and risk evaluation.

## Supporting a person to provide feedback to a service

- I facilitate a supportive, open and transparent environment that encourages people who use the service I work in, or their family members, carers, friends or advocates, to provide feedback. This includes raising concerns, making a complaint and or giving compliments.
- I actively seek feedback on my work from people I am providing care and support to.
- I fully explain to people how they can make a complaint and work to reduce the fear of negative consequences from making a complaint.
- I facilitate people who make a complaint to access support services, such as independent advocacy services.
- Where possible, I follow up on behalf of the person making a complaint and ensure that the complaint is responded to promptly, openly and effectively.

## Supporting a person to make an advance healthcare directive

- I facilitate and support a person in the creation of an advance healthcare directive, in line with their wishes.
- I adhere to the Assisted Decision-Making (Capacity) Act 2015 to ensure a person's advance healthcare directive is respected, and their will and preferences guide their treatment when they no longer have the capacity<sup>9</sup> to make certain decisions for themselves.

<sup>9</sup> 'Capacity' throughout this document means decision-making capacity. A person's decision-making capacity is assessed on the basis of their ability to understand, at the time that a decision is made, the nature and consequences of the decision, in the context of the available choices at that time.



## Minimising restrictive practices

- I recognise what restrictive practices are<sup>10</sup> and I uphold my duty of care to promote a restraint-free environment in the service I work in.
- I understand that a restrictive practice should only be approved when there is a real and substantive risk to a person and the risk to the person of not using this practice outweighs the risk of using it.
- Where it is deemed that a restrictive practice is required, I recognise that this should be regularly reviewed.

## Participating in decisions

- All decisions should be made with a person in a way that is fair, open, timely and impartial. I ensure that the person is supported, as far as is practicable, to make the decision in question and is given adequate time and support to do so. The person is given the opportunity to be heard and is central to the decision-making process.



**Resource 2** at the back of this guidance provides a decision-making aid that uses a human rights-based approach.

## 1.2 Fairness in practice

The following examples illustrate situations where the principle of fairness has been upheld and not upheld.

### FAIRNESS IS UPHELD

Marie is detained under the Mental Health Act 2001 in a mental health setting. Staff caring for Marie provide her with full information on her rights, including her right to legal representation, a second independent medical review and an independent review of her detention by a mental health tribunal. Staff go through this information with Marie and ensure her understanding. Staff facilitate Marie's access to these options. Providing this information and support enables Marie to challenge any issue in relation to her detention. It also ensures that staff fulfil their duty by ensuring people using their services are not unlawfully detained.

Liz has an intellectual disability and lived at home with her father until his death. As there were concerns that Liz might not be able to live independently, she was placed in a residential centre. Liz was unhappy in the residential centre and expressed her wish to live independently in the community. Her support team worked with her to put a support plan in place. Liz took part in all discussions about her options and managing risks. She was provided with all the relevant information and training she needed to ensure she understood the choices available to her and could actively participate in the decision-making process regarding her care. After extensive work with Liz, she was supported by staff to move back into the community 12 months later. She now lives independently and receives six hours of support per week.

<sup>10</sup> Restrictive practices are practices which intentionally or unintentionally limit a person's movement, communication and or behaviour.



Jack has an intellectual disability and lives at home with his parents. Jack's parents control his finances as they believe he is not capable of managing his own money. Jack attends a day centre during the week and has told staff that he would like to manage his own money. Staff are aware that Jack has never been supported to learn the skills of managing his own money. They feel he has the right to choose how he spends his own money and is capable of doing so with training and support. However, they also feel that Jack's parents know best and do not interfere with their wishes. Both the staff and Jack's parents have prevented Jack from managing his own money without legal justification. By making this decision without consulting him, the day care staff and Jack's parents have failed to uphold the principle of fairness.

In an acute healthcare setting, Eamon was recently given a terminal diagnosis. During the appointment, he was informed of his future care pathway but did not receive any additional information on his diagnosis, care plan or alternative care pathways to consider. It took Eamon a number of days to process his diagnosis. Eamon now has many questions about his future care and alternative treatments but does not know where to go to find this information. Eamon was not provided with all of the relevant information relating to his diagnosis and treatment options, and was not provided with a subsequent appointment at which he could follow up with any questions and request more information. Eamon was therefore not supported to make his own informed and independent choice regarding his care pathway. In doing this, the healthcare professional made the treatment decision for Eamon and failed to uphold the principle of fairness.

# 2



## 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 systems.

In health and social care settings, respect is shown in the actions towards a person by others and can be demonstrated by communicating in a courteous manner. This helps people feel valued through taking time to get to know them as a person and not as a number or a 'condition'.

Respect is central to providing person-centred care and support. People who use services must be listened to, and what is important to them must be viewed as important to the service. The principle of respect must be upheld regardless of a person's impairment or loss of capacity. Upholding the principle of respect also means that another person nominated by the person themselves, such as a family member, friend, or independent advocate is valued and listened to.

### How this principle links to legislation

| European Convention on Human Rights: | United Nations Convention on the Rights of Persons with Disabilities: |
|--------------------------------------|---|
| Article 1, Protocol 1                | Article 17  |
| Article 3                            | Article 19  |
| Article 8                            | Article 21  |
| Article 9                            | Article 22  |
|                                      | Article 23  |





## 2.1 How can I uphold respect in my day-to-day work?<sup>11</sup>

### Day-to-day communication

- When meeting a person using the service I work in for the first time, I take the time to introduce myself properly in order to connect with the person from the start. I ensure that the person understands what my role is.
- I take the time to listen to the person, and to understand them as an individual without judgment.
- I ensure that the person has all the available information necessary to make a decision about their care and support and has had their questions answered in a way they can understand. I check the person's understanding throughout this process. This may require the support of an interpreter or independent advocate if requested or needed by the person.
- When providing information to a person, I consider their preferences and their background as they describe these to me; for example previous life experience, educational attainment, literacy, culture and religious beliefs.
- I avoid using technical language to describe the person's condition or care. Instead, I use the person's own words and terms they can understand, in a format they can understand.

### Person-centred care and support

- I respect the person as the expert on their own life and support them to be involved in planning their care and support as much as possible.

- I ensure the person's care and support reflects the goals that are unique to the person and that are meaningful to them. A person's goals should not be dependent on available resources.
- I ensure that a person's care and support focuses on what is important to them, how they want to live and what support they want to achieve their goals. I recognise that their goals should be reviewed regularly and reflect their up-to-date will and preferences. This is reflected in planning their care and support.

### Supporting relationships

- I take time to get to know the person and their preferred lifestyle.
- I support the person and respect their wishes concerning maintaining and developing personal relationships with family and others. I do this with due regard for the person's own safety.

### Supporting the achievement of human rights

- I promote the person's right to access appropriate services.
- I support a person to realise all of their rights, including the right to decide where and how they wish to live, the right to have intimate relationships, to marry and to have a family.
- I know who to ask for advice or support within the service I work in if I observe or am concerned that a person's human rights are not being upheld. I also know where to look for information and support outside of the service I work in.

<sup>11</sup> This is not an exhaustive list but provides an indication of how respect can be supported and promoted.



**Resource 3** at the back of this guidance provides useful contacts if you are concerned that a person's human rights are not being upheld.



### Respecting property and personal information

- I respect the property and possessions of the people using the service I work in and ensure that they are able to access their possessions and property as required or requested.
- I respect the privacy of a person's personal information and medical records in line with data protection legislation. I share information only where there is a legal basis to do so.

### Participating in developing and evaluating services

- I encourage people to participate in the planning, design, delivery and evaluation of the service when the opportunity arises, and I recognise that their preferences should be reflected in the decisions that are made.
- If there are any changes in the service, I recognise that it is important to consult with the people who use the service and to take their views and preferences into consideration.

## 2.2 Respect in practice

The following examples illustrate situations where the principle of respect has been upheld and not upheld.

### RESPECT IS UPHELD

Liam is a new resident in a residential centre for older people, where he has chosen to live. When he meets a new member of staff, they introduce themselves to him. The staff learn about Liam's background, including his love of painting. When staff speak to Liam, they always address him by his first name as he has requested. They ask Liam if there is anything else that would help him settle into the centre. Liam asks for photos of his family and for his paintings to be displayed around his room. The staff support Liam in picking out and displaying the photos and paintings he would like to keep in his room. Staff have taken the time to get to know Liam and his preferences and have respected his request for access to his possessions.

Claire has an intellectual disability and lives in the community. She is attending a vocational education centre. She wishes to travel on her own by bus to her education centre each day. Claire's circle of support, which includes her parents and support worker, recognise that this is important to her. They listen to her and do not judge her because of her disability. They respect her personal preference and look at how they can best facilitate her choice.

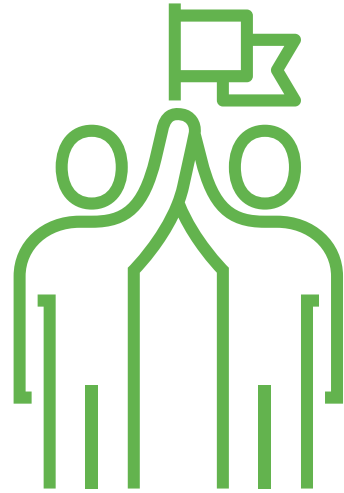


Eleanor has a physical disability and is supported to live independently at home. Following a recent hospitalisation with pneumonia, Eleanor was discharged from hospital into a rehabilitation centre without any consultation with her or her family. A person-centred approach was not applied when planning her care; she did not have the opportunity to participate in the planning of her care and her personal preferences were not taken into account. Eleanor does not know how long she will be in the rehabilitation centre. She is worried that when she returns home she will not receive the same level of care with the same people who had been supporting her previously.

Martha lives in a residential centre for older people and shares a room with another resident. Martha would like to keep her possessions and clothes in her own room but there is not enough space. Martha's possessions and clothes are kept in a storage room down the hall and staff choose Martha's clothes for her. Martha cannot access her possessions when she wishes. She would like to be able to personalise her room and choose her own clothes every day but she is not supported by staff to do so. Martha's right to access her possessions and property as desired was not upheld.



# 3



## 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.

Equality in health and social care is about ensuring that no one is discriminated against because of their status or characteristics. Discrimination occurs when someone is treated in a different way to someone else in a similar situation, or where people in very different situations are treated the same. Equity in health and social care means recognising that some people using services, because of their needs or circumstances, require additional help and support to achieve the best possible outcome. Providers have a duty of care to ensure fairness and equity for all people using services. A human rights-based approach strives to ensure that all people using services achieve the best possible outcome from the care and support they receive, regardless of their status or characteristics.

### How this principle links to legislation

| European Convention on Human Rights: | United Nations Convention on the Rights of Persons with Disabilities: |
|--------------------------------------|---|
| Article 14                           | Article 3<br>Article 5<br>Article 12<br>Article 25                    |





### 3.1 How can I uphold equality in my day-to-day work?<sup>12</sup>

#### Communicating respectfully

- I communicate respectfully with all people using the service I work in and ensure that each person is provided with information in a format and medium that is tailored to their needs and preferences regardless of who they are or their communication ability.

#### Providing quality care and support for all

- I support people who use the service I work in to get the care and support they need regardless of their age; civil status; disability; family status; gender; membership of the Traveller community; race, colour or nationality; religion and sexual orientation. The quality of care and support I provide is the same for everyone.
- Where people have more complex and varying needs, I do everything I can to meet these needs so as to ensure they can achieve the same outcomes as others. I do this, for example, by ensuring longer appointments are provided when necessary and possible, relevant information is accessible to everyone, and everyone has information about and access to relevant population health screening programmes, for example BreastCheck.

#### Presuming and supporting capacity

- I recognise that I must always presume that a person has capacity and that I never judge a person's decision-making ability based on age; civil status; disability, family status;

gender; membership of the Traveller community; race, colour or nationality; religion, or sexual orientation.

#### Promoting participation in society

- I take effective and appropriate steps to facilitate and promote a person's full inclusion and participation in society, for example supporting them in their right to vote, have relationships, and participate in and have valued roles within political, religious, social, cultural and self-help or advocacy organisations.

#### Encouraging equality and a human rights-friendly service

- I recognise the importance of there being a culture of equality within the service I work in, where all people receive equitable care and support so that they can achieve the best possible outcomes.
- I am aware that there should be no blanket policies, conditions or rules in place in the service I work in that can negatively impact people's human rights, for example their right to liberty.

#### Facilitating access to representation

- I support the right of people to access legal representation of their choice when requested or needed.
- I support the right of people to access independent advocacy representation of their choice when requested or needed.

<sup>12</sup> This is not an exhaustive list but provides an indication of how equality can be supported and promoted.



### 3.2 Equality in practice

The following examples illustrate situations where the principle of equality has been upheld and not upheld.

#### EQUALITY IS UPHELD

Sharon is an adult with an intellectual disability and wishes to have a sexual relationship with her boyfriend. Sharon's support workers recognise Sharon's right to a private and family life, including her sexual and reproductive rights. Due to previous conversations with Sharon about personal relationships, they have concerns about Sharon's capacity in relation to this decision and they want to make sure that she understands the decision she is making. With Sharon's agreement they conduct a capacity assessment in relation to her choice to have a sexual relationship. Sharon demonstrates her capacity to make this decision as she shows a clear understanding of personal and sexual relationships. She also understands the risks involved, including sexually transmitted infections and pregnancy, and is aware of various methods of contraception and how to access them if she chooses. She can clearly distinguish between relationships that are abusive and non-abusive. Sharon knows that staff are there for her if she needs their support or if she has any questions. By supporting Sharon in her decision, staff have taken the appropriate steps to ensure her right to respect for private and family life is upheld and to ensure she is not discriminated against because of her disability.

Annan is a Hindu. He is receiving care in an acute setting. Annan's condition has deteriorated and staff inform Annan's family that he is dying. Staff are aware of Annan's beliefs and discuss with his family how they can respect these beliefs. Just before death, Annan's family inform staff that he must be removed from his bed to the floor in keeping with his beliefs. Staff uphold the principle of equality and ensure Annan's religious beliefs are facilitated and respected.

#### EQUALITY IS NOT UPHELD

Sam is in his 90s and is living in an older person's residential centre. He likes to be able to walk down to the local shops and pub. In the centre, there is a policy in place to keep the front door locked in case residents with cognitive impairments leave the centre unattended. Sam does not have a cognitive impairment and this blanket policy impacts on his right to liberty. Sam is being discriminated against and is frustrated that he has to ask for permission each time he wishes to go outside.

English is not Nadia's first language and she often chooses to bring her friend, who speaks fluent English, with her to healthcare appointments to interpret and ensure she does not miss any important details. On one occasion, Nadia had a hospital outpatient appointment. However, her friend was not available to attend the appointment with her. Nadia phoned ahead to ask for an interpreter for the appointment but was told by the clinic secretary that this would not be possible. Nadia felt discriminated against and that no attempt was made to access an interpreter for her. As a result of not having an interpreter, Nadia did not understand everything that was discussed with her and her ability to make an informed decision was compromised.

# 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.

Dignity is central to the idea of human rights and all human rights are connected to human dignity. When human dignity is upheld in health and social care settings, it supports people using services to feel safe and improves their outcomes. It also improves working relationships and can result in positive outcomes for staff. Lack of dignity is a common theme in examples of abuse and neglect in health and social care settings, including malnutrition and dehydration; physical, psychological or sexual abuse; ignoring calls for help; unchanged bed sheets; not feeding people properly; pressure ulcers; poor personal care; being made to wear incontinence wear when unnecessary; restrictive practices; and bullying, patronising and condescending attitudes. A lack of dignity can result in feelings of insecurity, guilt, shame, worthlessness, anger, frustration, lack of confidence, inadequacy and reduced motivation. It can also result in reduced quality of care and support and decreased satisfaction among staff.

### How this principle links to legislation

| European Convention on Human Rights: | United Nations Convention on the Rights of Persons with Disabilities: |
|--------------------------------------|---|
| Article 3                            | Article 3   |
| Article 5                            | Article 15  |
| Article 8                            | Article 16  |
|                                      | Article 17  |
|                                      | Article 22  |





## 4.1 How can I uphold dignity in my day-to-day work?<sup>13</sup>

### Meeting basic needs

- I ensure people using the service I work in have their basic needs met, for example food, clothing and personal care (including assisting with oral and dental care), and that they feel safe, comfortable, valued and respected.
- I ensure that they have access to appropriate food and hydration so that they do not suffer from malnutrition or dehydration. I ensure that food and drink is always within a person's reach and offer assistance if support is required to eat or drink.
- I ensure that people are not neglected or treated in any way that is likely to cause harm. For example, I make sure that no one is left in a soiled state.

### Maintaining privacy

- I make sure to respect the privacy of people when supporting them to undress, bathe and dress.
- I discuss a person's health and care in a private setting or, in a situation where there is no private space available, I make all efforts to ensure their privacy; for example lowering my voice or moving closer to the person so as not to be overheard by others.
- I make sure to properly cover a person during a physical examination or when I am assisting them with their intimate care.

- I avoid rushing a task so as not to impact their privacy and dignity.

### Communicating sensitively

- I address and refer to people who use the service I work in by their preferred name and gender pronoun.
- I communicate with people in a way that acknowledges and respects their individuality, dignity and personal identity. I do this whether or not the person is able to communicate verbally. If a person is unable to communicate verbally, I work with the person and others who know them, as well as with other team members, to understand the best way to communicate with them. I strive to make sure that they understand me and that I understand them.
- I take care not to patronise or be condescending towards a person regardless of their age or any other status.
- I ensure that a person's dignity is maintained at all times even if they are unconscious, and unable to communicate.

### Supporting a person's preferred lifestyle

- I always enquire about a person's preferred lifestyle, including routines, pets, personal care, clothing preferences, religious and cultural preferences, and facilitate their lifestyle as much as possible. This can be something as simple as providing preferred food options during mealtimes. Where a person's preferred lifestyle is not easily known, I consult with others who know them to ascertain their past and present preferences.

<sup>13</sup> This is not an exhaustive list but provides an indication of how dignity can be supported and promoted.



## Minimising restrictive practices

- I ensure that a person is supported to move around freely. For example, I ensure that a person is not confined to a bed or chair when this is unnecessary.

## 4.2 Dignity in practice

The following examples illustrate situations where the principle of dignity has been upheld and not upheld.

### DIGNITY IS UPHELD

Fiona is pregnant and has started to experience depression. She has been referred to a midwife with mental health expertise in her local maternity hospital. Fiona does not want others finding out about her depression. The mental health midwife ensures that her privacy is respected at all times. When Fiona is called for her appointment, although the room is a few minutes walk from the waiting area, the midwife ensures they are in the consultation room and cannot be overheard before they begin talking.

Graham has an intellectual disability and is on an end-of-life pathway with a terminal illness. He is receiving care in his own home. Graham is weak and has difficulty swallowing. Staff ensure that Graham is supported to eat and drink. Staff have upheld his dignity by ensuring these basic needs are met. Staff have taken time to get to know Graham and they learn that his favourite drink is whiskey and coke. On the occasions when he requests it, Graham is supported to have his favourite drink with thickener. Staff have also upheld Graham's dignity by taking the time to get to know him and facilitating his preferences.



Daniel has difficulties communicating verbally and is admitted to hospital with complications associated with his diabetes. The healthcare practitioners do not speak to Daniel about what care they are providing to him or what interventions are being carried out, because he cannot communicate verbally. In addition, staff do not assess whether Daniel can understand them and if there are other ways to communicate with him. Daniel is not provided with additional support to help him to communicate with staff and therefore is not involved in any decisions regarding his care.

Rebecca is an 80-year-old woman with severe arthritis. She lives in a residential centre. Rebecca needs support to get out of bed and is often told to relax and to have her breakfast in bed. Rebecca knows this is because there is not enough staff to help her to the dining room. Rebecca's preference, however, is to get out of bed and to have her meals in the dining room with other residents. On one occasion, low staffing levels in the centre led to Rebecca not being facilitated to leave her bed for an entire day. Rebecca was told they could not get her out of bed because of staff shortages and was given an incontinence pad to wear. She becomes very upset as she is able to use toilet facilities with assistance and feels her dignity has been compromised.

# 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. In a health and social care setting, autonomy involves the person using a service making informed decisions about their care, support or treatment.

In a health and social care setting, people may require different levels of support to assert their autonomy and make their own decisions. This means staff have a key role in this process. The ability to be autonomous, and make decisions, can and must be supported and developed. Respecting and supporting autonomy is important in health and social care as it is a fundamental aspect of person-centred care and support.

Respecting a person's autonomy in health and social care involves meaningful communication. It is important to recognise that it can also involve negotiation and compromise when a person's will and preferences impact on the rights, care and safety of others. A person's autonomy may also be impacted when there is a legal basis for it not to be upheld.

### How this principle links to legislation

| European Convention on Human Rights: | United Nations Convention on the Rights of Persons with Disabilities: |
|--------------------------------------|---|
| Article 3                            | Article 3   |
| Article 5                            | Article 12  |
| Article 8                            | Article 14  |
|                                      | Article 19  |







## 5.1 How can I uphold autonomy in my day-to-day work?<sup>14</sup>

### Seeking consent

- I make sure that I communicate clearly and effectively with the person using the service I work in. I use language or other means of communication that they can understand and do not use medical or social care jargon. I always support the person in their decision-making process in relation to their care and support.
- I make sure that the person is provided with adequate and relevant information about their care and support options, including the advantages and disadvantages of each option, to ensure they can make a fully-informed decision.

### Understanding and respecting a person's will and preferences

- I make sure that I understand and regularly review the will and preferences of a person to ensure that I can promote and support their autonomy when assisting in or supporting their decision-making process.
- In order to make sure a person's autonomy is upheld, I support their choice in relation to care and support, regardless of whether or not I believe it is the right decision. I understand that a person has the right to make a decision that may appear to me to be unwise.
- I ask for advice or support if I observe or am concerned about undue influence on a person's decision-making.

<sup>14</sup> This is not an exhaustive list but provides an indication of how autonomy can be supported and promoted.

### Supporting capacity and responding accordingly

- I always presume a person has capacity and work to fully support them to make a decision for themselves.
- I recognise that I cannot presume that a person lacks capacity in relation to a certain matter or decision on the basis that the decision they make seems unwise to me.
- If a person has been assessed<sup>15</sup> as lacking capacity under the Assisted Decision-Making (Capacity) Act 2015 in relation to a certain matter or decision and if an intervention is urgent and it is unlikely that the person will recover capacity to make a decision in the short term, I ensure that any action I take is proportionate to the seriousness of the issue at hand and minimises any restrictions to their human rights. In addition, I make every effort possible to ensure that their past and present will and preferences have been determined. This includes considering the views of any person named by the person themselves, whether a family member, a friend, or independent advocate, and consider any written documentation or any other record (such as an advance healthcare directive) and ensure that any decision made takes these into account.

<sup>15</sup> The functional test is a time specific and issue specific test, set out in the Assisted Decision-Making (Capacity) Act 2015, for the assessment of a person's capacity where concern exists. A person is determined to lack capacity to make a decision if they are unable to understand the information relevant to the decision, retain that information long enough to make a voluntary choice, use or weigh that information as part of the process of making the decision and communicate his or her decision in whatever way they communicate.



- I recognise that capacity is time and issue specific. Although a person might have been assessed as not having capacity to make a decision at a particular moment in time, I understand that when it is relevant and possible for me to do so, I should make sure that their capacity is reviewed and that changes are made accordingly.
- I recognise that, where capacity is assessed as limited, the person should be supported to increase capacity to make an informed decision or reduce a restriction through skills development, in line with their preferences.

### **Minimising restrictive practices**

- I always explore options other than restrictive practices when a person displays behaviour that challenges, or behaviour that is disruptive. I also make sure that when a restrictive practice is used, it is proportionate to the behaviour it is being used to restrict; is the least restrictive option; is applied for the shortest possible time; and is subject to a timely review. I understand that this is also an opportunity to trial alternatives that are less restrictive and or for a shorter period of time.

### **Supporting participation**

- I encourage the participation of people in the assessment, planning, delivery and evaluation of their care and support as much as possible and as much as the person wishes. I recognise that a person's wishes to engage may change over time and where a person chooses not to engage, I regularly review their interest to re-engage.

### **Supporting independent living**

- I make sure that I support people as much as possible to maintain or develop their ability to live independently and develop the skills necessary for community living.



## 5.2 Autonomy in practice

The following examples illustrate situations where the principle of autonomy has been upheld and not upheld.

### AUTONOMY IS UPHELD

Jane has a physical disability and had been living in a residential centre. However, she wished to live at home. Following discussion and assessment, her support team in the residential centre felt that this was not ideal, as she was considered to be a person with high needs. Jane and the team discussed this and she understood and agreed that she would not receive the same level of care at home that she would have in the residential centre. Jane's wishes were respected and she was supported to take a measured risk. This was not about discharging Jane from the service, but about supporting her to transition from the residential centre and continuing to provide her with care in a different setting. Staff supported Jane in exercising her autonomy by understanding and respecting her will and preferences and supporting her to live independently. Staff communicate with Jane on a regular basis to make sure that her new living situation is working well for her and identify any additional supports that she may need.

### AUTONOMY IS UPHELD

Kieran had a stroke a number of years ago and is being cared for in a residential centre. Since then, he has had difficulty swallowing and communicating verbally. Medical advice was to introduce percutaneous endoscopic gastrostomy (PEG) feeding, where he would be fed through a tube into his stomach. All information relating to Kieran's treatment options were explained to him in an accessible way over a six-month period. He was facilitated to ask questions and express his choice of treatment throughout this time. Kieran fully understood all of his options. He did not want PEG feeding to be introduced as he felt it would impact on his enjoyment of the social aspect of eating and mealtimes. As a result, the procedure did not go ahead. Instead, staff in the residential centre arranged extra support for him when he was eating. Through correctly seeking consent and supporting Kieran to make a fully informed decision regarding his preference for eating, staff have upheld his autonomy.

Richard is an inpatient in an acute setting; he is suffering from complications associated with Parkinson’s disease. Richard likes to eat quickly and on more than one occasion he has nearly choked on his meal. Staff assessed Richard’s situation and prescribed for his food to be cut up. Richard was not consulted regarding this decision. He was not provided with information in the right format to ensure his understanding of the process and he was not consulted with regarding the next steps in his care plan. Richard does not want his food to be cut up and wishes he had been involved in the decision-making process and supported to participate in the planning of his care.

John has severe heart failure and is currently in hospital with shortness of breath. He is aware of the seriousness of his condition and has no problems understanding the information he is given by the staff. He tells his daughter that he does not wish to receive cardiopulmonary resuscitation (CPR) or ventilation in the event of a cardiac arrest. John’s daughter informs staff of his decision. However, staff do not record this in John’s notes. No healthcare professional discussed resuscitation and future options with John in the event of a cardiac arrest and he did not receive any information about making an advance healthcare directive. A few days later, John experiences a cardiac event and all attempts are made to resuscitate him. Staff on duty are unaware of John’s wishes on resuscitation and do not consult with his family to determine what his will and preferences are. As no efforts were made to ascertain and record John’s past will and preferences, the principle of autonomy has not been upheld.



## Extended case studies



**JIM**

**Jim has dementia and lives in a residential centre for older people. Patrick, a nurse, has recently started work in the centre.**

On his first day, Patrick introduces himself to Jim and greets him warmly. He sits with Jim and asks him how he is. He speaks slowly to Jim and uses simple language. Throughout his first week at the centre, Patrick familiarises himself with Jim's notes; reading about the hobbies Jim once engaged in, his family and his views and beliefs. Patrick is aware of various techniques which could be used in order to make Jim as comfortable as possible, such as reminiscence therapy and art therapy. Patrick speaks to Jim's family and friends and listens to their opinions on the various interventions that may help him.

Patrick wants to build a relationship with Jim but this can be challenging as Jim frequently becomes confused and angry. This occurred on one occasion when Patrick assisted Jim in changing his clothes and Jim became frustrated with the process. Although Patrick was under time pressure, he respected Jim's frustrations and gave him time before trying again. Patrick ensures Jim's privacy is protected when performing intimate care tasks such as supporting Jim to bathe and dress.

**Respect**

is upheld. Patrick takes the time to introduce himself properly to Jim when they first meet and he speaks to him in a way that Jim can understand.

**Autonomy**

is upheld. Patrick makes every effort to determine Jim's individual needs and preferences. He also talks to Jim's family and friends and listens to their suggestions based on their personal knowledge of Jim.

**Dignity**

is upheld throughout Jim's care pathway. Patrick does not rush tasks that affect Jim's personal privacy. He communicates with Jim in a way that respects Jim's individuality and personal needs and preferences.

**Fairness**

is upheld. Patrick follows Jim's wishes in relation to sharing information about his care. Patrick welcomes feedback on the care and support he provides to Jim.

**Equality**

is upheld. It is important to understand the impact that treating Jim the same as everyone else would have on him. Patrick understands that this could lead to indirect discrimination.

Jim has told Patrick that he would like his wife to be kept up-to-date about the care he is receiving. With Jim's consent, Patrick meets with Jim's wife at regular intervals to keep her informed about Jim's care. Patrick also views these meetings as opportunities to get feedback from Jim's wife about the care and support provided to Jim.

By spending time with Jim, Patrick begins to understand him more – learning about his history, what works for him, what has not worked for him, and what triggers certain emotions. Jim's notes reveal that he enjoys company and Patrick works to understand how to interact with him on a level he feels comfortable with. Patrick initially engaged with Jim as he would with any other person using the service, in terms of making conversation. However, this had put a lot of strain on Jim. Every subsequent interaction Patrick has with Jim involves him being present and caring, but not necessarily vocal. Jim likes art and once a week Patrick arranges an outing with him to a local art gallery. When communicating with Jim, Patrick makes remarks rather than asking Jim questions, placing no onus on Jim to answer him or engage with him if he would prefer not to. These short interactions allow Patrick to build a more trusting relationship with Jim.



## CLAUDIA

**Claudia is in her late 50s and has a physical disability. She lives in a residential care centre. She recently saw an advertisement on TV about BreastCheck and wondered why she had not yet received a letter regarding this.**

Claudia asked the nurse on duty why she had not received a letter and even though the nurse did not know, she did not follow up on Claudia's query. Claudia found it upsetting that her query was not taken seriously and spoke to her support worker, Fiona, about her concerns. Fiona found out that the centre had received the letter but had discarded it. Claudia arranged an appointment with the resident GP to discuss the matter. At Claudia's request, Fiona accompanied Claudia to her appointment.

Claudia explained what had happened and although her GP did not know how or why this had happened, he explained to Claudia how she could access the screening programme and provided her with written information about it. Claudia was glad she had visited the GP as she felt she had been listened to and taken seriously.

### Respect

was not upheld. Claudia's nurse did not provide adequate answers to her questions and did not provide her with information on the options available to her. She was not supported to access and realise her rights.

### Dignity

was not upheld. Claudia was not taken seriously by the nurse.

### Equality

was not upheld as Claudia's care did not promote equity of outcomes. It is important that her will and preferences are respected in the same way as others, regardless of her characteristics or status.

### Fairness

was upheld in that Claudia was supported in making a complaint by her care worker. The centre manager upheld fairness by making efforts to rectify the situation by putting proper procedures in place.

### Autonomy

was upheld. Claudia was supported throughout the process by her support worker who ensured her will and preferences are central to it.

Claudia wanted to make a complaint about not receiving the letter as she felt that her health had potentially been put at risk. However, Claudia did not know how to do this as there was no information available in the centre. She asked for assistance from Fiona, who helped her write a letter of complaint to the centre manager. The centre manager sent a letter of apology to Claudia, explaining what had happened to her letter from BreastCheck and stating that all efforts would be made to ensure she received a date for her screening appointment as soon as possible. Claudia was also reassured that procedures would be put in place to prevent this from happening to anyone in the centre again.



## MARK

**Mark is an 80-year-old adult with hearing loss living in a nursing home. Over the past number of years, Mark's sight has deteriorated and he is now legally blind. Mark's wife died a number of years ago and he does not have any children. He is close to his niece, Marie, who visits him regularly. The resident GP comes to see Mark, as he is experiencing severe abdominal pain and vomiting. His GP sends him to the emergency department for further tests, and Mark is diagnosed with appendicitis.**

The plan is to proceed with surgery to remove Mark's appendix. Mark's doctor, James, meets with him in his six-bed ward when Marie is visiting him. James introduces himself and asks Mark if he would like anyone to be with him when he receives information about his surgery. Mark says that he would like his niece to stay with him when discussing his care. James closes the curtains halfway around his bed. He knows that Mark has difficulty hearing and therefore moves closer to speak with Mark explaining that he will need surgery.

### Respect

was upheld. Mark was provided with information about his condition and treatment, and had his questions answered in a way he understands. Mark's doctor showed respect in addressing his hearing loss by moving closer to speak with him.

### Equality

was upheld when Mark's will and preferences were respected regardless of his characteristics or status.

### Dignity

was upheld. He was communicated with in a way that acknowledged his personal identity and individuality. However, by not closing the curtain fully, his physical privacy was compromised.

### Fairness

was upheld as there was a clear and fair process in place governing informed consent and Mark was provided with accessible information in a format of his choice on his treatment options. Mark was supported to participate in the decision-making process.

### Mark's autonomy

was upheld throughout this process, resulting in him making an informed decision to consent to surgery freely and without duress.

James ensures he follows the necessary guidelines for good practice in seeking consent to treatment. He explains to Mark the benefits and risks of the proposed surgery and the consequences of not having surgery. He explains the procedure using simple language and avoids complex medical terminology where possible. He asks Mark how he would like to receive the information. As Mark has difficulties with his sight and hearing, he is provided all relevant written information about the procedure in large bold print which he is able to read. Mark is fully informed and actively involved in the process. James encourages him to ask questions and he checks Mark's understanding throughout the discussion. He gives Mark time to reflect on the information and to think of further questions to ask.

Mark is anxious about the surgery and has a number of questions. Mark's doctor spends time answering these questions clearly, which eases his fears. Mark gives his consent to undergo surgery for his appendicitis. James is aware that Mark came to this decision by himself.

## Resource 1: Key human rights relevant to health and social care services and how they link to the FREDA principles



This resource describes key human rights set out in the European Convention on Human Rights Act (ECHR) 2003 and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) 2006 which are relevant to health and social care.

### **Right to life**

This relates to Article 2 of the ECHR and Article 10 of the UNCRPD. This means that health and social care services will fulfil their obligation to protect the right to life and to refrain from unlawfully interfering with the right to life. It covers situations where a person's life may be at risk and decisions are being made to withdraw life-sustaining treatments or not to resuscitate a person. It can also relate to a person experiencing suicidal thoughts or posing a risk to other people's lives.

### **Prohibition of and freedom from torture or inhuman or degrading treatment or punishment**

This relates to Article 3 of the ECHR and Articles 15 and 16 of the UNCRPD. This is relevant where a person is at risk of serious harm including where a person is neglected or cared for in a way that causes serious harm, suffering or humiliation. It can be relevant where someone receives continuing treatment that causes serious harm and suffering or where a person's need for pain relief is not assessed and responded to.

### **Right to liberty and security**

This relates to Article 5 of the ECHR and Article 14 of the UNCRPD. This means that a person's liberty may not be interfered with without the legal power to do so based on a capacity assessment or risk of immediate harm to self or others.

### **Right to a fair trial and access to justice**

This relates to Article 6 of the ECHR and Article 13 of the UNCRPD. This covers all aspects of procedural fairness. It is relevant when other rights, such as the right to liberty or the right to respect for private life, are at issue. It includes the right to participate effectively in proceedings and in some cases a public hearing, and the right to legal representation.

### **Right to respect for private and family life**

This relates to Article 8 of the ECHR and Articles 19, 22 and 23 of the UNCRPD. Private life can be interpreted to include personal choices, relationships, physical and mental wellbeing and access to personal information. It includes confidentiality and privacy of medical information. It also relates to supporting a person to communicate and participate in community life.



## Resource 1: Key human rights relevant to health and social care services and how they link to the FREDA principles



### **Right to freedom of thought, conscience, religion, expression and opinion**

This relates to Articles 9 and 10 of the ECHR and Articles 3 and 21 of the UNCRPD. This right protects everyone's right to freedom of thought, conscience, religion, expression and opinion. It includes the right of people to put thoughts and beliefs into action either alone or in a community with others. Both religious and non-religious beliefs are protected, as is the right to change religion or belief. For a belief to be protected, it must be serious, concern important aspects of human life or behaviour, be sincerely held, and be worthy of respect in a democratic society. This right also relates to the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of a person's choice.

### **Prohibition of discrimination**

This relates to Article 14 of the ECHR and Articles 3, 5, 17 and 25 of the UNCRPD. This can relate to situations where a person is denied access to services or treatment on any ground such as sex, race, colour, language, religion, political or other opinion, national origin, association with a national minority, property, birth or other status. It also relates to people being treated differently to others under comparable circumstances on account of their

characteristics, or where people with very different characteristics are treated the same. This can lead to unequal outcomes. In an Irish context, prohibition of discrimination also relates to the Equal Status Acts 2000-2015. The grounds for discrimination set out in the Equal Status Acts 2000-2015 are narrower than those set out in the ECHR.

### **Protection of property**

This relates to Article 1 of Protocol 1 of the ECHR and Article 12 of the UNCRPD. A person is entitled to the peaceful enjoyment of their possessions. Possessions and property have a wide meaning, including land, houses, leases, money and personal property. A person's property or possessions and the way they use them cannot be interfered with, except in the public interest and when subject to the conditions provided for by law.

Ireland is a signatory to a number of international human rights treaties, which are all of importance in international human rights law. For further information: <https://www.ohchr.org/EN/pages/home.aspx>

# Linking the European Convention on Human Rights Act 2003 and the United Nations Convention on the Rights of Persons with Disabilities 2006 to the FREDA principles

## Fairness

| <b>ECHR:</b>   | <b>UNCRPD:</b>  |
|--|---|
| <b>Article 3:</b> prohibition of torture                       | <b>Article 5:</b> equality and non-discrimination                               |
| <b>Article 5:</b> right to liberty and security                | <b>Article 12:</b> equal recognition before the law                             |
| <b>Article 6:</b> right to a fair trial                        | <b>Article 13:</b> access to justice  |
| <b>Article 8:</b> right to respect for private and family life | <b>Article 21:</b> freedom of expression and opinion, and access to information |
| <b>Article 10:</b> freedom of expression                       |   |
| <b>Article 14:</b> prohibition of discrimination               |   |

## Respect

| <b>ECHR:</b>   | <b>UNCRPD:</b>  |
|--|---|
| <b>Article 3:</b> prohibition of torture                       | <b>Article 17:</b> protecting the integrity of the person                       |
| <b>Article 8:</b> right to respect for private and family life | <b>Article 19:</b> living independently and being included in the community     |
| <b>Article 9:</b> freedom of thought, conscience and religion  | <b>Article 21:</b> freedom of expression and opinion, and access to information |
| <b>Article 1, Protocol 1:</b> protection of property           | <b>Article 22:</b> respect for privacy  |
|  | <b>Article 23:</b> respect for home and the family                              |

## Equality

| <b>ECHR:</b>                                     | <b>UNCRPD:</b>                                     |
|--|--|
| <b>Article 14:</b> prohibition of discrimination | <b>Article 3:</b> general principles               |
|  | <b>Article 5:</b> equality and non-discrimination  |
|  | <b>Article 23:</b> respect for home and the family |
|  | <b>Article 25:</b> health                          |

## Dignity

| <b>ECHR:</b>   | <b>UNCRPD:</b>   |
|--|--|
| <b>Article 3:</b> prohibition of torture                       | <b>Article 3:</b> general principles   |
| <b>Article 5:</b> right to liberty and security                | <b>Article 15:</b> freedom from torture or cruel, inhuman or degrading treatment or punishment |
| <b>Article 8:</b> right to respect for private and family life | <b>Article 16:</b> freedom from exploitation, violence and abuse                               |
|  | <b>Article 17:</b> protecting the integrity of the person                                      |
|  | <b>Article 22:</b> respect for privacy   |

## Autonomy

| <b>ECHR:</b>   | <b>UNCRPD:</b>  |
|--|---|
| <b>Article 3:</b> prohibition of torture                       | <b>Article 3:</b> general principles  |
| <b>Article 5:</b> right to liberty and security                | <b>Article 12:</b> equal recognition before the law                         |
| <b>Article 8:</b> right to respect for private and family life | <b>Article 14:</b> liberty and security of the person                       |
|  | <b>Article 19:</b> living independently and being included in the community |

## Resource 2: Decision-making flow chart<sup>16</sup>



This flow chart is a helpful tool for staff when making decisions in relation to a person's care. The case study below relates specifically to a situation that can arise in services for end-of-life care, but the process is adaptable across settings.

### 1. What is the decision?

Bill is on an end-of-life pathway and wishes to be discharged from hospital to return home to die, against medical advice.

### 2. Who is affected and how?

Bill is directly affected. If he were to remain in hospital against his wishes, he would have less control in his final stage of life. Bill's family are affected by the decision. Bill's consultant who will be discharging Bill is also affected by this decision.

### 3. Who has made the decision?

Bill's consultant knows that this is Bill's decision to make, but he is concerned Bill will not receive adequate physical care and pain management at home.

### 4. Will the decision affect anyone's rights as set out in the ECHR Act 2003?

Bill's consultant considers which of Bill's rights are impacted in this situation. Discharging Bill will support his personal choices, relationships and mental wellbeing. It will uphold the FREDA principle of Respect, in addition to Article 8 (the right to respect for private and family life), and Article 5 (the right to liberty) of the ECHR. However, discharging Bill may lead to him not receiving appropriate care, such as pain relief. This could impact on the FREDA principle of Dignity, and Article 3 (prohibition of torture) of the ECHR.

### 5. If the decision involves a human rights restriction, is it lawful, legitimate and proportionate?

Bill's decision to leave may impact on his rights. Therefore the following test must be applied: there must be law or policy that allows the restriction of the rights and there must be legitimate reason for restricting the right and the restriction must be absolutely necessary. Bill's consultant is legally obliged to respect Bill's wishes even though he feels it is an unwise decision. It is Bill's wish to return home and avail of community palliative care.

### 6. If the decision involves a human rights restriction, is it lawful, legitimate and necessary?

Bill's consultant explores with him the palliative care and other supports available to him at home. He ensures and documents that Bill has all of the available information necessary to make a decision about his care and support, in a way he can understand, and has had his questions answered in a way he can understand. With Bill's permission, he refers Bill to the palliative care and other supports in the community.

<sup>16</sup> This flow chart was developed by the British Institute of Human Rights and has been adapted for an Irish context with permission.

## Resource 3: Useful contacts and further reading



### **HSE ‘Your Service Your Say’**

**Tel:** 045 880 429 or **lo-call:** 1890 424 555.

**Email:** [yoursay@hse.ie](mailto:yoursay@hse.ie)

**Homepage:** [www2.hse.ie/services/hse-complaints-and-feedback/your-service-your-say.html](http://www2.hse.ie/services/hse-complaints-and-feedback/your-service-your-say.html)

### **HSE Office of the Confidential Recipient**

**Tel:** 087 665 7269 or **lo-call:** 1890 100 014.

**Email:** [leigh.gath@crhealth.ie](mailto:leigh.gath@crhealth.ie)

**Homepage:** [www2.hse.ie/services/hse-complaints-and-feedback/report-a-concern-about-a-vulnerable-adult-in-care-to-the-confidential-recipient.html](http://www2.hse.ie/services/hse-complaints-and-feedback/report-a-concern-about-a-vulnerable-adult-in-care-to-the-confidential-recipient.html)

### **HSE National Safeguarding Office**

**Tel:** 061 46 1165 (9.00am – 5.00pm Monday to Friday) or

**HSE Information Line:** 1850 24 1850

(8.00am to 8.00pm Monday to Saturday)

**Email:** [safeguarding.socialcare@hse.ie](mailto:safeguarding.socialcare@hse.ie)

**Local HSE Adult Safeguarding and Protection Team:**

[www.hse.ie/safeguarding](http://www.hse.ie/safeguarding)

### **Health Information and Quality Authority (HIQA)**

Concerns About Services, Health Information and Quality Authority, George’s Court, George’s Lane, Smithfield, Dublin 7

**Tel:** 021 240 9646.

**Email:** [concerns@hiqa.ie](mailto:concerns@hiqa.ie)

**Homepage:** [www.hiqa.ie](http://www.hiqa.ie)

### **Irish Human Rights and Equality Commission**

Your Rights, Irish Human Rights and Equality Commission, 16-22 Green St., Dublin 7

**Tel:** 01 858 3000 or **lo-call:** 1890 245 545.

**Email:** [YourRights@ihrec.ie](mailto:YourRights@ihrec.ie)

**Homepage:** [www.ihrec.ie](http://www.ihrec.ie)

### **Office of the Ombudsman**

18 Lower Leeson Street, Dublin 2, D02 HE97.

**Tel:** 01 639 5600 or **lo-call:** 1890 223 030.

**Email:** [info@ombudsman.ie](mailto:info@ombudsman.ie)

**Homepage:** [www.ombudsman.ie](http://www.ombudsman.ie)

### **Safeguarding Ireland**

**Tel:** 061 461 358.

**Email:** [info@safeguardingireland.org](mailto:info@safeguardingireland.org)

**Homepage:** [www.safeguardingireland.org](http://www.safeguardingireland.org)

## Resource 3: Useful contacts and further reading



This section lists a series of published resources that may be useful for staff working in health and social care services. This list is not exhaustive and does not include all the resources that may be relevant to all staff. Staff should seek and identify the best available, and most current evidence relevant to their work.

### Published documents

|   |   |
|---|---|
| <p><b>National Consent Policy</b><br/>Health Service Executive, 2019</p> <p>Homepage: <a href="http://www.hse.ie">www.hse.ie</a></p>  | <p><b>'Hello my name is...' Checklist for Implementation</b><br/>Health Service Executive, 2016</p> <p>Homepage: <a href="http://www.hse.ie">www.hse.ie</a></p>   |
| <p><b>Supporting People's Autonomy: A Guidance Document</b><br/>Health Information and Quality Authority, 2016</p> <p>Homepage: <a href="http://www.hiqa.ie">www.hiqa.ie</a></p>  | <p><b>Guidance for Designated Centres: Risk Management</b><br/>Health Information and Quality Authority, 2014</p> <p>Homepage: <a href="http://www.hiqa.ie">www.hiqa.ie</a></p>   |
| <p><b>Guidance on promoting a care environment that is free from restrictive practice: Disability Services</b><br/>Health Information and Quality Authority, 2016</p> <p>Homepage: <a href="http://www.hiqa.ie">www.hiqa.ie</a></p> | <p><b>Guidance on promoting a care environment that is free from restrictive practice: Older People's Services</b><br/>Health Information and Quality Authority, 2016</p> <p>Homepage: <a href="http://www.hiqa.ie">www.hiqa.ie</a></p> |

### Key legislation

|   |   |
|---|---|
| <p><b>European Convention on Human Rights Act 2003</b></p> <p>Homepage: <a href="http://www.irishstatutebook.ie">www.irishstatutebook.ie</a></p>            | <p><b>United Nations Convention on the Rights of Persons with Disabilities 2006</b></p> <p>Homepage: <a href="http://www.un.org">www.un.org</a></p>               |
| <p><b>The Equal Status Acts 2000-2015</b></p> <p>Homepage: <a href="http://www.irishstatutebook.ie">www.irishstatutebook.ie</a></p>                         | <p><b>Assisted Decision-Making (Capacity) Act 2015</b></p> <p>Homepage: <a href="http://www.irishstatutebook.ie">www.irishstatutebook.ie</a></p>                  |
| <p><b>The Irish Human Rights and Equality Commission Act 2014</b></p> <p>Homepage: <a href="http://www.irishstatutebook.ie">www.irishstatutebook.ie</a></p> | <p><b>The Charter of Fundamental Rights of the European Union</b></p> <p>Homepage: <a href="http://www.citizensinformation.ie">www.citizensinformation.ie</a></p> |



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**Guidance on a  
human rights-based  
approach to care and  
support in health and  
social care services.**

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*Supporting you to implement  
national standards*



# Health Information and Quality Authority

An tÚdarás Um Fhaisnéis  
agus Cáilíocht Sláinte

## **Health Information and Quality Authority**

Dublin Regional Office  
George's Court, George's Lane  
Smithfield, Dublin 7  
D07 E98Y

T: +353 (0) 1 814 7400

E: [info@hiqa.ie](mailto:info@hiqa.ie)

W: [hiqa.ie](http://hiqa.ie)