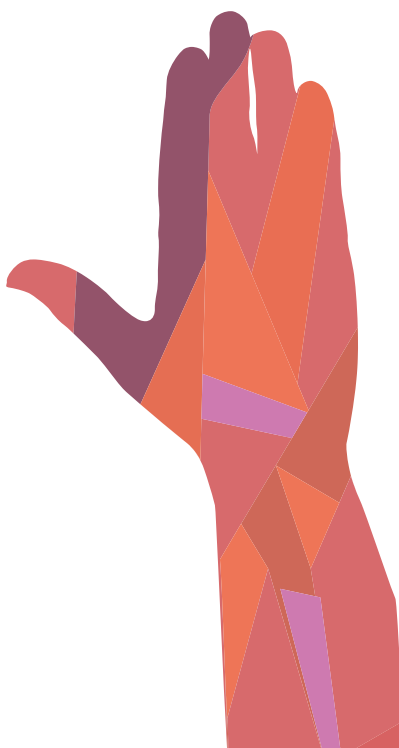
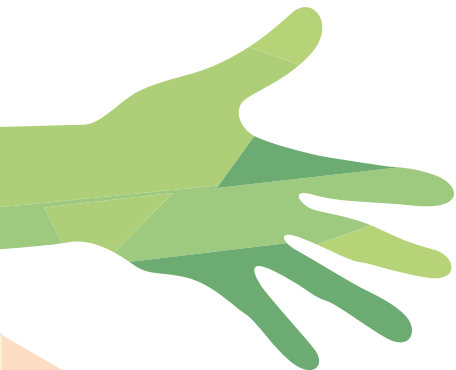




**Health  
Information  
and Quality  
Authority**

An tÚdarás Um Fhaisnéis  
agus Cáilíocht Sláinte

# The Fundamentals of **ADVOCACY** in health and social care





## **About the Health Information and Quality Authority**

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

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

- setting standards for health and social care services
- regulating social care services
- regulating health services
- monitoring services
- health technology assessment
- health information
- the National Care Experience Programme.





## Setting national standards for health and social care

Under the Health Act 2007, HIQA is responsible for the development of national standards for health and social care services. National standards are a set of high-level outcomes that describe how services can achieve safe, quality, person-centred care and support. National standards aim to promote quality improvements and improve the experience of people using health and social care services. Principles have been developed that underpin all national standards. The principles are: responsiveness, a human rights-based approach, safety and wellbeing, and accountability, which work together to ensure person-centred care and support.



Principles to underpin national standards for health and social care services.



## **Tools to support the implementation of national standards**

HIQA develops tools to assist service providers and staff to understand and implement national standards in their setting. The tools enable service providers to deliver services that are person centred, responsive, and accountable and that promote safety, wellbeing and human rights.

Advocacy is a key element in all national standards published by HIQA and is highlighted in the *National Standards for Adult Safeguarding* and the *Guidance on a Human Rights-based Approach in Health and Social Care Services*. Advocacy is essential to ensure person-centred care and support in health and social care services.

This booklet is a tool that has been developed alongside an online learning course on advocacy and an educational video on advocacy. These tools are designed to help implement national standards, enhance understanding of advocacy, and support people to have their human rights met.



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## **Purpose of this booklet**

This booklet will help you to understand advocacy in health and social care. It has been developed as an introduction to an online learning course *The Fundamentals of Advocacy in health and social care*. These learning tools describe what advocacy is, the different types of advocacy, and the role of people working in health and social care in relation to advocacy.

HIQA recommends that all health and social care staff complete the online course to improve their knowledge and understanding of advocacy and to help them implement the national standards.





## Online learning course: The Fundamentals of Advocacy in Health and Social Care



This online learning course can be used by health and social care staff to learn more about advocacy. The course is available on the HSeLanD website, [www.hseland.ie](http://www.hseland.ie), and in the standards and quality section of the HIQA website at [www.hiqa.ie](http://www.hiqa.ie).

By completing the course, you will understand:

- what **advocacy** is and why it is important
- how to support people to have their **will and preference** met and have their voices heard
- that advocacy is a necessary part of your role as a health and social care worker and what you can do to ensure people's **autonomy** and **human rights** are upheld
- the boundaries of your role as an advocate, including identifying possible **conflicts of interest**
- how to ensure people are aware of **independent advocacy** services and when to support people to access independent advocacy services.





## What is advocacy?

Advocacy is about supporting and empowering people to communicate their will and preference, secure their human rights, or represent their interests.

### **Advocacy:**

- **supports** people to speak up and be understood, so they can express their wishes, needs and wants, and ensure they are listened to
- **helps** people to access information, to understand options and to consider all possible factors and outcomes of a decision
- is **empowering** people to assert their human rights, make informed decisions about their life, make choices, achieve a desired outcome or address a grievance
- is **representing** a person, where required, to help them express their will and preference or to achieve a desired outcome
- is **enabling** and **respecting** the human rights of people who are unable to participate in decisions about themselves or express their will and preference
- is **preventing** and **reducing** the escalation of issues over time, such as abuse or exploitation.







Advocacy is **not** about:

- making decisions for others
- convincing someone to make a certain decision
- ignoring a person's will and preference
- only reacting to problems that arise.



## What is independent advocacy?

Independent advocacy:

- is provided to a person with their consent
- involves speaking up for and standing alongside a person or a group
- ensures that the will and preference of the person is placed at the centre of the process
- is provided by advocates who are free from any conflict of interest, and are independent of family, service provider or system's interests.

Staff have a responsibility to make people aware of independent advocacy services. Where appropriate and with consent, they can support a person to contact an independent advocacy service.





Independent advocacy can be provided as **empowerment** advocacy or **representative** advocacy.

- **Empowerment advocacy** aims to empower and support a person to submit a complaint themselves.
- **Representative advocacy** aims to represent a person in submitting a complaint and includes speaking up on their behalf.

If a person is not in a position to communicate their will and preference, or where it is not possible to obtain them, **non-instructed advocacy** may be required.

Non-instructed advocacy:

- is delivered by a professional trained in non-instructed advocacy
- involves representing the person by taking additional steps to determine, as far as possible, the person's wishes, feelings and desired outcomes
- ensures that the person's will, preference and rights remain central to all decisions affecting them.

When providing non-instructed advocacy, advocates can observe a person and their situation, look for alternative means of communicating with them, and gather information from different sources, such as a service provider or general practitioner (GP), to build a picture of the person and their preferences.





## **When is independent advocacy needed?**

Advocacy is a key part of the role of all health and social care staff. However, there are times when it is necessary to involve an independent advocate.

Independent advocacy may be required if a person:

- asks for it
- feels that, after exhausting all options, an issue cannot be resolved internally
- feels uncomfortable speaking to staff
- continues to have difficulty understanding or retaining information provided by staff
- continues to experience difficulty communicating their will and preference with support from staff
- cannot be appropriately supported due to a real or potential conflict of interest
- feels their human rights are not being respected
- requires support to maximise their decision-making capacity.

With the person's consent, an independent advocacy service can be contacted by staff, by the person themselves or by their family.

Where a person is not in a position to provide consent or instruct an advocate, then non-instructed advocacy is the approach taken.





## Other types of advocacy

There are several types of advocacy. The appropriate type depends on the situation and on individual preference. A person should always be able to choose the type of advocacy they wish to use.

Staff in health and social care settings have an important role in promoting advocacy services and supporting people to understand and access different types of advocacy.

- **self advocacy** is when a person is supported to say what they want and access their rights. For example, staff can make sure a person is given information in a way that they understand and listen to what they have to say.
- **patient complaints advocacy** supports people who want to make a complaint about an experience they had in a health and social care service. For example, staff can support a person to access the services of a patient complaints advocate who would help them to make the complaint.
- **group advocacy** is when people facing a common problem come together to support each other. For example, staff can host an advocacy group themselves or arrange for an advocate to facilitate group advocacy within their service.

You can learn more about other types of advocacy in the online course ***The Fundamentals of Advocacy in health and social care.***





## **What is will and preference?**

A person's will and preference is about the choices they make, their wants and their wishes.

Respecting a person's will and preference helps to achieve a person-centred approach to care and respects a person's human rights. Will and preference is central to the advocacy process.

Will and preference can be communicated through words, signs and gestures, facial expressions, behaviours and actions. A person's preferences will change from time to time.

Staff can support people to express their will and preference by:

- listening to the person and ensuring they have a suitable way of communicating their will and preference
- putting the person at the centre of all decision-making about their care
- supporting the person to understand all options in relation to their life and care
- supporting a person to access independent advocacy.





## **What is the role of health and social care staff?**

An advocate is a person who protects and promotes people's human rights, while also respecting their autonomy, privacy, dignity, values, preferences and diversity.

Advocacy is a key part of the role of all health and social care staff. However, there are times when it is necessary to involve an independent advocate. For example, an independent advocate is needed if staff are trying to balance the interests of their employer with the interests of the person in their care.





The role of health and social care staff in relation to advocacy includes:

- **listening** to people and supporting them to have their voices heard
- **supporting** people to have their will and preference met
- **respecting** people's autonomy and confidentiality
- **identifying** the need for independent advocacy as soon as possible
- making **information** about independent advocacy services available
- **supporting** people to access independent advocacy services when needed
- **working in partnership** with independent advocates to support the person they are working with
- **facilitating or arranging** group and or peer advocacy within the service.







## **What important skills do health and social care staff need?**

All health and social care staff have a responsibility to empower people to express their wishes, will and preference in relation to their care. Health and social care staff also have a responsibility to understand the legislation relating to advocacy that applies to them. Other important skills that will support advocacy in health and social care are:

- communication
- empowerment
- empathy.





Effective **communication** involves:

- **listening** openly to the person's concerns, needs and wants
- spending **time** getting to know the person, their interests, preferences and life experiences, and to fully **understand** what is going on in their life
- providing **information** in a way that the person can **understand** and giving them **time** to digest the information and to ask questions.





You can **empower** service users by:

- being **respectful** and **non-judgemental** about the decisions they make
- building a relationship with them, where they feel comfortable discussing their feelings and their will and preference
- **encouraging** the person to become involved in decisions about their own life
- focusing on the person's **strengths** and **abilities**
- ensuring they are aware of available advocacy services
- **supporting** them to understand and uphold their human rights.





You can show **empathy** to people by:

- **listening** to people and taking their concerns seriously
- providing friendly and **consistent** care
- connecting with the person by making an effort to understand how they are feeling
- staying **present** when speaking with the person and not getting distracted
- **reflecting** on the person's **will and preference** and considering the best approach to manage the situation.





## Examples of advocacy

Read the scenarios below to learn about some of the different types of advocacy and the role of staff in relation to these types of advocacy.

### Paul's story

Paul has dementia and sometimes finds it difficult to communicate and understand medical information. Paul is currently in hospital and the medical team have recommended surgery as the best option for treatment. The doctor has a discussion with Paul's family about the options. Paul is very frustrated as he feels that decisions are being made without his input.



## **Self-advocacy**

Self-advocacy is when a person is supported to access their rights, to say what they want and ensure they are listened to.

A diagnosis of dementia does not mean that Paul is not capable of making decisions about his own care.

Supported by some staff members, Paul calls a meeting to make it clear to his family and the doctor that he is the only person who can make decisions about his care. Paul asks the staff and his family to make sure that they provide him with all the information that he needs to make important decisions, using language that is easy for him to understand.

The role of health and social care staff in supporting Paul to self-advocate involves:

- ensuring that Paul is at the centre of any decision-making that affects him
- providing Paul with relevant information that he can understand
- ensuring that Paul has opportunities to voice his will and preference and to make his own decisions.



## Claire's story

Claire entered a nursing home on a short-term basis at the start of the COVID-19 pandemic, but is still there more than two years later. Claire wants to return home, but her family and the staff think it is best for her to remain in the nursing home. Claire has seen a poster about an independent advocacy service and she asks a staff member to make a referral for her.



### **Independent advocacy**

Independent advocacy is provided to a person with their consent and includes speaking up for and standing alongside a person or a group.

The independent advocate listens to Claire to determine her will and preference, and seeks to ensure that her human rights are understood and upheld.





The independent advocate attends a meeting and supports Claire to discuss the issue with her family and staff. The independent advocate supports Claire to voice her concern to her family and nursing home staff.

The role of health and social care staff in supporting Claire to access independent advocacy involves:

- providing Claire with information about independent advocacy services
- supporting Claire to contact an independent advocacy service, with her consent
- encouraging communication between Claire and her independent advocate
- ensuring Claire has enough time to prepare for her meetings with the advocate
- ensuring Claire can communicate with her advocate in a way that is suitable for her and that she has privacy during her meetings
- providing ongoing support to Claire throughout her advocacy journey.







## Hannah's story

Hannah has an intellectual disability and attends a disability service. Hannah's father is in charge of managing her money but Hannah begins to question 'Is that not my money?' Hannah is concerned about speaking to her father about this, as she is afraid he will not listen to her. In the disability service, Hannah attends a peer advocacy support group. She learns that some of her peers have experienced similar problems.



### **Peer advocacy**

Peer advocacy is when a person works with an advocate who has had similar personal experiences.

Some of the other members in Hannah's group had a similar experience to her and agreed that it is a serious issue.





They encouraged and motivated Hannah to contact an independent advocacy organisation, who can more appropriately support Hannah with her situation.

The role of health and social care staff in supporting Hannah to access peer advocacy involves:

- providing Hannah with information about peer advocacy
- supporting Hannah to prepare for and attend the peer advocacy groups in her service
- supporting Hannah to contact independent advocacy organisations who can more appropriately support Hannah in her situation
- providing ongoing support to her throughout her advocacy journey.





## HIQA advocacy resources

To learn more about advocacy, please complete the online learning course, *The Fundamentals of Advocacy in health and social care*, available on HSeLanD at [www.hseland.ie](http://www.hseland.ie) or in the Standards and Quality section of the HIQA website [www.hiqa.ie](http://www.hiqa.ie). The course is aimed at anyone working in health and social care services and is also available to anyone who has an interest in this area. HIQA have also developed an educational video on advocacy which can be found on the HIQA website.



## Additional resources

HIQA has developed a number of online learning courses to support staff working in health and social care to implement national standards and guidance.

- **Adult safeguarding online learning course**  
HIQA, in partnership with the Mental Health Commission, developed an online learning course entitled *National Standards for Adult Safeguarding: Putting the standards into practice* to support frontline health and social care staff to implement the safeguarding standards in their day-to-day practice.





- **Rights-based care online learning modules**  
HIQA developed an online learning course on rights based care, with four modules on *Applying a Human Rights-based Approach in Health and Social Care* to enhance understanding of human rights and support health and social care staff to put a human rights-based approach into practice in their day-to-day work.



**Module 1:** Introduction to Human Rights in Health and Social Care

**Module 2:** Role of Good Communication in upholding Human Rights

**Module 3:** Putting People at the Centre of Decision-making

**Module 4:** Positive Risk-taking.





## National standards and guidance

National standards and guidance developed by HIQA include:

- *National Standards for Safer Better Healthcare*
- *National Standards for Residential Services for Children and Adults with Disabilities*
- *National Standards for Residential Care Settings for Older People in Ireland*
- *National Standards for Adult Safeguarding*
- *Guidance on a Human Rights-based Approach in Health and Social Care Services.*

These are available on the HIQA website [www.HIQA.ie](http://www.HIQA.ie).

## Advocacy Services

- The National Advocacy Service for People with Disabilities (NAS)  
Website: [www.advocacy.ie](http://www.advocacy.ie)
- The Patient Advocacy Service (PAS) (includes nursing homes)  
Website: [www.patientadvocacyservice.ie](http://www.patientadvocacyservice.ie)
- Sage Advocacy  
Website: [www.sageadvocacy.ie](http://www.sageadvocacy.ie)





- Social and Health Education Project (SHEP)  
Website: [www.socialandhealth.com](http://www.socialandhealth.com)
- Empowering People in Care (EPIC)  
Website: [www.epiconline.ie](http://www.epiconline.ie)

The HSE has a list and contact details of advocacy services available in Ireland at [www.hse.ie](http://www.hse.ie). You can find this list under Advocacy Services.

### **Other Support Organisations**

- [The Decision Support Service](#)
- [HSE National Office for Human Rights and Equality Policy](#)
- [Irish Hospice Foundation](#)
- [Money Advice and Budgeting Service \(MABS\)](#)
- [The Office of the Ombudsman](#)
- [Safeguarding Ireland](#)
- [Citizens Information Board](#)





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