



INCLUSION IRELAND

National Association for People with an Intellectual Disability

Submission to the Department of Health

**On the Patient Safety, Complaints and Advocacy
policy**

June 2017

**This document is written in font 12 Verdana in line with Inclusion
Ireland plain English guidelines.**

1. About Inclusion Ireland

Established in 1961, Inclusion Ireland is a national, rights based advocacy organisation that works to promote the rights of people with an intellectual disability.

Inclusion Ireland uses a human rights-based approach to its work. This recognises persons with an intellectual disability as rights holders with entitlements, and corresponding duty bearers and their obligations. Inclusion Ireland seeks to strengthen the capacities of persons with an intellectual disability to make their claims and of duty bearers to meet their obligations.

The vision of Inclusion Ireland is that of people with an intellectual disability living and participating in the community with equal rights as citizens, to live the life of their choice to their fullest potential. Inclusion Ireland's work is underpinned by the values of dignity, inclusion, social justice, democracy and autonomy.

2. Introduction

The Department of Health is in the process of developing a new patient safety, complaints and advocacy policy. The Department has initiated a consultation process to ask the general public what they think should be included in the new policy.

It is important that people with disabilities have an opportunity to take part in consultation processes such as this. In reflecting our own values as an organisation, Inclusion Ireland engaged with people with disabilities in compiling this submission. Their views on key issues are dispersed throughout this paper.

The Department of Health have posed a number of questions on different aspects of the policy to be considered. Below are Inclusion Ireland's responses to the questions asked by the Department of Health.

3. Healthcare complaints process

What is working well about the healthcare complaints process?

Currently, if a person wants to make a complaint about a health or social care service, they can contact the relevant service provider or make a complaint through the HSE's 'Your service, Your say'. If the complaint is from a person living in residential care, or on their behalf, a complaint can be made to the Confidential Recipient. Complaints can also be made to the Ombudsman or Ombudsman for Children's Office.

There are many staff within health and social care settings who are very empathetic towards patients and will often go above and beyond the call of duty to support people using a service and families. However, this is largely dependent on individuals and people's experiences can vary widely.

The HSE's website (www.healthcomplaints.ie) is a useful source of information on how to make a complaint, who to make a complaint to and where to go for help. It is a useful resource but there are improvements that can be made to make it more accessible.

The existence of independent mechanisms such as the Ombudsman and the Confidential Recipient provide a level of accountability and transparency. The independent nature of these bodies is a strength.

The Confidential recipient, the Ombudsman and the Ombudsman for Children's Office all produce annual reports and data on complaints received. The case studies published in these reports provide an important insight into the experiences of children and adults using health and social care services. These reports regularly highlight cases where the

rights of people with disabilities have not been upheld and as such, are an important contribution.

The recent establishment of the National Patient Safety Office within the Department of Health is a positive development and will hopefully provide leadership and coordination to policy and practice in this area.

What is currently not working well about the healthcare complaints process

- **Accessibility issues**

Systems are not straightforward or user friendly. There is a lack of accessible information on complaints procedures and a lack of awareness on the processes that do exist. There is often no standard process in each health or social care service in terms of making a complaint.

Resources such as healthcomplaints.ie and 'Your Service, Your Say' are not well known to people with intellectual disabilities.

"Some people in the service have heard of 'Your service, your say' but others have not. The complaint forms need to be visible. No one in my service knows about them or where they are¹".

Even when people are aware that such resources exist, they can be inaccessible to persons with disabilities due to the language or formats used.

- **Length of time**

Through our advocacy work, Inclusion Ireland is aware that complaints can take a very long time to be resolved. In many cases this takes much longer than the statutory timeframe. Inclusion Ireland is aware of complaints taking two and more years to be resolved, in some cases.

¹ Consultation with self-advocates, Inclusion Ireland, June 2017

In addition, complaints to the Ombudsman and Ombudsman for Children's Office can only be made once the local remedy has been exhausted, which can take a very long time. These offices also cannot review clinical complaints at present.

- **Poor implementation**

Complaints can be made under the Disability Act 2005 in relation to assessment of need as well as access to buildings, services and information.

The Disability Act obliges public bodies to appoint an Access Officer to coordinate issues around access. However, in a report by the Ombudsman into how hospitals handle complaints, around half of the hospitals did not have an Access Officer in place².

- **Lack of systemic change**

The frequent cases of abuse highlighted by regulatory bodies and the media are an indication that complaints processes are not functioning effectively and are failing to address systemic issues. It is not enough for a complaints process to deal with complaints on a case by case basis. It must be possible to identify systemic issues, learn from previous errors and improve services. Launching their 2015 report the Ombudsman noted people were reluctant to complain about health issues as they believed it would make no difference³.

Figures provided by the HSE in April 2017 showed that over 1,000 complaints were filed under the Disability Act for failure to carry out an assessment within the specified timeframe⁴. 88% of the complaints were upheld. However, despite the existence of a complaints mechanism, it is

² Office of the Ombudsman (2015). Learning to get better. An investigation by the Ombudsman into how hospitals handle complaints. Dublin: Office of the Ombudsman

³ Office of the Ombudsman (2016). Annual report 2015

⁴ Dáil Éireann Debate. 9th May 2017. Vol. 949 No. 3

having a very limited effect in terms of improving the timeframes for assessments.

The Disability Appeals Officer is effectively defunct. They have not published a written determination since April 2015 and have not published an annual or financial report since 2011⁵. This situation has led to families entering the courts to have their child assessed on time⁶.

- **Perceived victimisation**

People often tell Inclusion Ireland that they will not take a complaint as they fear it may adversely affect their access to services. Some people have reported being referred to Tusla on foot of making a complaint. Both of these issues are highlighted in a report by NUI Galway⁷. One parent had her three children effectively locked out of HSE services for making a complaint.

The Ombudsman also noted a low level of health complaints and that people had told the office that they were afraid of adverse consequences of complaining⁸.

Outline suggestions you have on how the healthcare complaints process could be improved?

- **Accessible information**

Information on making a complaint and support to do so should be available in a variety of formats, such as easy to read and braille as well as in video format.

⁵ Department of Health. About the disability appeals officer. <http://health.gov.ie/contact-us/the-disability-appeals-officer/>

⁶ O'Faolain, A. (2017). Families sue over HSE failure to assess children with special needs. Irish Times, May 15, 2017

⁷ Kline, J. & Flynn, E. Access to Justice for children with cognitive disabilities. Centre for Disability Law and Policy, NUI Galway.

⁸ Office of the Ombudsman (2016). Annual report 2015

“Complaint policy and complaint forms should be in easy-to-read⁹ ”

The accessibility of the website could be improved by increasing font sizes, using plain English and adding features such as Browse Aloud.

- **Implement recommendations from Ombudsman’s report, ‘Learning to get Better’ (2015)**

In the report, ‘Learning to get Better: an investigation into how public hospitals handle complaints’, a number of recommendations were made as to how complaints processes could be improved. These should be implemented across all health and social care settings.

These recommendations included:

- Clear pathways describing how to make a complaint
- Clear identification of the designated person to take the complaint
- Specified time frames for response to a complaint
- Easy to read and accessible information, including video formats, describing complaints procedures
- A designated place to contact if you need more information or someone to talk to if the process is not accessible

- **Use complaints to improve services**

It is important to develop a culture of learning from complaints within health and social care settings so that services can be improved. A mechanism for sharing findings from the investigation of complaints should be developed so that learning can be shared across different health and social care settings¹⁰ .

- **An equality and rights focus**

⁹ Consultation with self-advocates, Inclusion Ireland, June 2017

¹⁰ Office of the Ombudsman (2015). Learning to get better. An investigation by the Ombudsman into how hospitals handle complaints. Dublin: Office of the Ombudsman

The healthcare complaints process should have an equality and rights focus. It should be consistent with legislation such as the Assisted Decision Making (Capacity) Act 2015 in that it should support persons with disabilities to express their own will and preference on healthcare decisions.

4. Complaints advocacy/support service

What is working well about the healthcare complaints advocacy/support service?

Complaints advocacy/support services are defined in the consultation document as a service to help empower the person in the healthcare complaints process.

The healthcomplaints.ie website lists a range of organisations that provide advocacy support to members of the public, such as the Citizens Information Board, the National Advocacy Service, Sage and the Irish Patients Association.

Advocacy services play a vital role in enabling people with disabilities to enjoy their rights and entitlements. The independent nature of many advocacy and support services is a positive quality.

What is currently not working well in the provision of a healthcare complaints advocacy/support service?

The National Advocacy Service provides a representative advocacy to people with disabilities. However, demand for the service is high and waiting lists can be long. The Personal Advocacy Service, as provided for under the Citizens Information Act 2007, has yet to be introduced.

Many of the organisations providing advocacy supports do not provide a representative advocacy service and they do not have statutory powers to investigate complaints.

The National Advocacy Service has highlighted the difficulties that a lack of statutory powers can have. They report some services not allowing the advocate access to records or to attend meetings¹¹.

Currently, funding for advocacy for people with a disability, including self-advocacy, representative advocacy and peer advocacy, is provided by different Government departments. There is a need for a consistent, joined-up approach. A broad range of advocacy services and supports should be available to people with a disability.

Hiqa, the Ombudsman, and regulators such as the Medical Council, the Nursing and Midwifery Board of Ireland and Corú for Social Care Workers all play a role in the complaints and advocacy process. However, the role of each organisation is not widely understood. There is a need for greater public awareness and accessible information on who these organisations are and the role they play in supporting the public.

Outline suggestions you have on how to improve healthcare complaints support/advocacy services?

- The Personal Advocacy Service, as provided for under the Citizens Information Act 2007, must be introduced without further delay as an interim measure
- A National Advocacy Authority should be established that has responsibility for coordination and oversight of all advocacy services to persons in receipt of public services

¹¹ National Advocacy Service for People with Disabilities, 2016, Annual Report.

- People should be supported to engage in self-advocacy
- Complaints and advocacy services should be guided by a code of rights
- Complaints and advocacy services should be in compliance with human rights and equality law such as the Equal Status acts, UN treaties such as the UN Convention on the Rights of Persons with Disabilities, the Convention on the Elimination of all forms of Discrimination Against Women and the Convention on the Rights of the Child.
- Reinstate the Disability Appeal Officer and promote the office.
- Services should be consistent with the Assisted Decision Making (Capacity) Act and provide support for people to make their own decisions on healthcare
- “Staff members need to listen to residents about the challenges they face when making complaints¹²”.
- “People should also have a key worker or an advocate to help make a complaint, and should be encouraged to do this privately¹³”

5. Key elements of definitions

What should be the key elements of a healthcare complaints definition?

The language used in the definition needs to be more straight forward. For example, what does “adversely affect” mean? Can it mean that

¹² Consultation with self-advocates, Inclusion Ireland, June 2017

¹³ Consultation with self-advocates, Inclusion Ireland, June 2017

someone is not happy with the service they received? Can it mean that someone feels like they were treated badly? Can it mean someone didn't understand the process and made a mistake making a complaint? The definition should be expressed in plain English.

What should be included as key elements of a complaints, advocacy, support service definition?

The definition should:

- Focus on upholding the rights of the person but also include the promotion of welfare, wellbeing and rights as well as upholding rights¹⁴
- Focus on a person's own will and preference.
- Include self-advocacy
- Make reference to a charter of rights

6. New policy to provide leadership and policy direction to improve health complaints, advocacy and support services

What needs to be included in the overall patient safety complaints and advocacy policy?

- **Independence**

The complaints and advocacy service should be independent of the health system. Access to independent advocacy has been recommended by numerous reports, such as the Ombudsman's investigation into

¹⁴ Mongan, D., Long, J., Farragher, L. (2016). Models of patient advocacy: evidence brief. Dublin: HRB.

complaints in hospitals and Hiqa's report on the investigation into the Midlands Regional hospital¹⁵.

- **Monitoring and evaluation**

The policy should include a mechanism for reviewing and evaluating effectiveness. Data on complaints received and how they were handled should be published periodically. Persons with disabilities should be involved in the monitoring and evaluation of services.

- **Accessibility**

Accessibility should be a key principle throughout the policy. This includes accessible language used in all information leaflets, forms and other written documents as well as accessible websites. The complaints and advocacy process should also be accessible to those who don't have access to or don't wish to use online services.

There should be a dedicated advocacy liaison person in every section of health and social care services who meets with people or families of people with intellectual disabilities. This person should be trained in advocacy and in communicating with people with intellectual disabilities. This person should make themselves known to all people using services so that they know they can make a complaint or speak up.

- **Focus on equality and rights**

The policy should be underpinned by equality and human rights principles and by the values of autonomy, democracy, respect and dignity. The policy should be consistent with the guidelines issued by the National Safeguarding Committee as well as the Assisted Decision Making (Capacity) Act 2015.

¹⁵ Hiqa (2016). Review of progress made at the Midland Regional Hospital, Portlaoise, in implementing recommendations following HIQA's investigation. Dublin: Hiqa.

The policy should include the development of a code of practice for complaints and advocacy services.

- **Person-centred**

The policy should allow for supports to a person depending on their needs and wishes. This should range from information, signposting, and support for self-advocacy to more intensive one on one supports and representative advocacy service.

There should be procedures in place in the event that someone needs a little more support when advocating for themselves. Families have reported to Inclusion Ireland, that a person with an intellectual disability can often be ignored when they express concern about what is happening to them and their body. It is often attributed to misunderstanding and this is not right or fair for the person involved.

The policy should make provision for legal support/consultation where appropriate. This might be in cases which may result in successful legal action or where legal advice might help the person to understand why the legal route may not be successful in a particular case¹⁶ .

- **Address systemic issues**

It is critical that there is some mechanism for learning from complaints and making changes to policies and practices as a result of complaints. There should also be a system for sharing learning (in line with FOI and data protection) across health and social care settings to prevent similar occurrences arising again.

- **Support for staff**

All staff, including those involved in handling of complaints, need information and training on human rights and equality as well as law and policy such as the Assisted Decision Making (Capacity) Act 2015. All

¹⁶ As in Western Australia. Example from: Mongan, D. , Long, j. Farragher, L. (2016). Models of patient advocacy: evidence brief. Dublin: HRB.

Being subject to a complaint can be challenging for the staff concerned. Staff should be supported to change practices where the need for this has been identified.

7. Summary of recommendations

- The policy should be underpinned by equality and human rights principles and promote the values of autonomy, dignity and respect
- Policies and procedures should be clear, accessible, user friendly and widely known and understood
- Information should be made available in accessible formats
- Access to independent advocacy should be available and it should be person-centred to suit the needs of the person
- There should be an independent body to coordinate patient advocacy services as well as the other forms of advocacy
- Systemic issues should be identified and addressed and policies and procedures changed to minimise reoccurrence of similar complaints.