

Irish Deaf Society Submission to the

Public Consultation on Draft Legislation to Update the Mental Health Act, 2001

08/04/2021

Introduction

The Irish Deaf Society (IDS) is the only national Deaf-led representative organisation of the Deaf and Hard of Hearing, and it serves the interests and welfare of the Deaf community. It provides a number of educational, personal and social services to Deaf and Hard of Hearing children, adults and their families.

The Irish Deaf Society is recognised as a Disabled Peoples Organisation (DPO) under the UN Convention on the Rights of Persons with Disabilities (CRPD). IDS are members of the World Federation of the Deaf and the European Union of the Deaf and have consulted with international Deaf representative bodies in relation to their experience during the pandemic.

Our Advocacy service has clearly identified a need for mental health services based on our one-to-one contact with clients presenting with a wide range of issues, concerns and complaints. A lack of accessible public and private services has led to an increase in anxiety, depression and suicide in the Deaf community.

Approximately 40-50% of Deaf individuals are likely to experience mental health difficulties at some time in their lives. In comparison, the lifetime prevalence of mental health difficulties among the general population is significantly lower at 25%.

On the following pages we describe the lived experience of Deaf people in accessing mental health services and expand on ways in which the Mental Health Act can be updated to improve these experiences.

1. Definitions

- 1.1. 'Deaf', 'Hard of Hearing', and 'Deafened' are appropriate terms to describe a Deaf person. In 1991 the World Federation of the Deaf (WFD) and the International Federation of Hard of Hearing People voted to use "Deaf and Hard of Hearing" as an official designation.
- 1.2. Language such as 'hearing Impaired', 'Deaf & Dumb', 'Deaf-Mute', and 'hearing Loss' put Deaf people in biased comparison to hearing people, and negatively implies an ideal state as hearing, thus labelling Deafness as a problem. These terms focus on the medical perspective while the Deaf community rather focus on the Cultural perspective.



2. Guiding Principles

- 2.1. The 'Guiding Principles' section of the report looks at rights to autonomy and self-determination for the patient/client. For a Deaf person, Irish Sign Language (ISL) interpretation ensures full access to the information needed to act autonomously
- 2.2. There is now a legal requirement under the Irish Sign Language Act 2017 to ensure provision of interpreter services for a Deaf person in their interactions with any public services. As this legal obligation does not include private services, Deaf people do not always have access to the relevant Mental health services.
- 2.3. Under Article 25 on the UNCRPD, Ireland has committed to ensuring that people with disabilities have access to the same range, quality and standard of free or affordable health services as others. This commitment is not being met.
- 2.4. If an Irish Sign Language Interpreter is not provided, medical professionals often look to family of the Deaf person to make decisions or to assist with communication. Under the Irish Sign Language Act 2017, only a registered ISL Interpreter must be used - if possible, one with Mental Health experience. Training in mental health interpreting must be made available to all interested ISL interpreters.
- 2.5. For a Deaf person to enjoy the highest standard of mental health care, a level of Deaf awareness amongst professionals is necessary. Deaf Awareness Training highlights the experience of Deaf people and the issues and barriers that they face. Deaf awareness means having an understanding of Deaf culture and an ability to communicate in a Deaf-friendly way. Even with an ISL Interpreter provided, Deaf people have had negative experiences in mental health services, due to lack of awareness of Deaf people. Only when this awareness is gained can a professional work with a Deaf person at the high standard that is necessary.
- 2.6. The Expert Group Review acknowledges that there should be a move away from historically 'paternalistic' attitudes towards clients. The Deaf Community endures such paternalistic attitudes from society and Deaf Awareness Training would inform professionals of this issue.

3. Criteria for detention

The Irish Deaf Society do not currently have any comments to make under this heading.

4. Authorised Officers

The Irish Deaf Society do not currently have any comments to make under this heading.



5. Interdisciplinary approach to care and treatment

- 5.1.** In recommendation 98 the Expert Group Review recommends that every patient should have a right to information.
- 5.2.** Recommendation 99 refers to complaints' mechanisms and ensuring the patient is aware of any such mechanisms.
- 5.3.** The above 2 recommendations further underpin the importance of full access to information for the Deaf client in their interactions with Mental Health services and staff.
- 5.4.** In situations where a referral has been made for the Deaf person, it is likely that the professional may be inexperienced in relating to and assessing Deaf people with mental health problems. This can in turn result in incomplete or inaccurate information being provided. This underpins once again the importance of Deaf awareness training in such professions.

6. Changing timeframes

- 6.1.** Excessive duration in hospital stays can be due to the lack of appropriate facilities in the community for accommodation and support and can be particularly distressing for d/Deaf patients due to poor communication and experiences they may have had in hospital settings previously.
- 6.2.** In 2015, the Mental Health Reform briefing developed in collaboration with Chime stated that the detention of d/Deaf patients with mental health difficulties in facilities is noticeably higher than hearing patients. Mental health problems in Deaf people can be neglected unless they become acute, and result in an admission under the Mental Health Act.

7. Enhancing safeguards for individuals

- 7.1.** A delay in intervention, due to communication needs or lack of accessible services can result in Deaf people presenting at a time when they are at higher risk. When working with Deaf people, professionals need to be aware of this.
- 7.2.** Due to high demand for ISL interpreters, there may not always be availability – specifically in emergency situations. This can compromise the Deaf person's dignity and potentially lead to dangerous misunderstandings.
- 7.3.** Deaf people may experience delays because those taking their requests for appointments are unaware of the process for providing access such as the process of booking an ISL Interpreter.



- 7.4. Delays in access to services and difficulties in diagnosis (including misdiagnosis) often lead to prolonged duration of mental health difficulties. In certain cases, severe mental health difficulties such as schizophrenia and psychosis may go untreated for several years.
- 7.5. There must be a low threshold for the referral of Deaf people to specialist Mental Health and Deafness services for assessment, so that the gatekeeping is not by the least experienced clinicians.

8. Mental health tribunals

The Irish Deaf Society do not currently have any comments to make under this heading.

9. Change of status from voluntary to involuntary

- 9.1. In relation to patient's rights, the Expert Group Review (in Recommendation 25) states that all patients "should be fully informed of their rights, including information relating to their proposed treatment as well as their rights regarding consent or refusal of treatment and their right to leave the approved centre at any time." It should be noted that Deaf people do not necessarily have a high level of literacy, and must be given the opportunity to have written material signed to them.
- 9.2. Such rights are fundamental to the patient's engagement with Mental Health Services and it is especially crucial that any and all accommodations required by the Deaf patient be made so that all relevant information is accessed fully and fully understood.

10. Capacity

- 10.1. Under the capacity heading it is stated that "Individuals are entitled to notification about certain decisions and to respond in relation to admission and treatment decisions as far as is practicable". This notification and response require additional support for the Deaf person whose first language is Irish Sign Language. At a minimum this requires the engagement of an interpreter.
- 10.2. In mental health situations decision-making is crucial and it is vital that the person has the capacity to understand.
- 10.3. The Mental Health Act underpins this as follows:
A person lacks the capacity to make a decision if he or she is unable—
 - (a) to understand the information relevant to the decision,
 - (b) to retain that information,
 - (c) to use or weigh that information as part of the process of making the decision, or



(d) to communicate his or her decision (whether by talking, writing, using sign language, assisted technology, or any other means) or, if the implementation of the decision requires the act of a third party, to communicate by any means with that third party.”

- 10.4. The Expert Group Review alludes to ‘institutional influence’ in recommendation 18, whereby an individual is over-awed by the Mental Health Professional and will go along with whatever they say without fully understanding the situation.
- 10.5. This can often apply to Deaf people as they are overwhelmed by the language barrier in addition to a more general ‘institutional influence’ which stems from the history of the Deaf community. This again underpins the case for the provision of interpretation and Deaf awareness training for Mental Health staff.

11. Consent to treatment

- 11.1. In relation to consent, Recommendation 83 states that “all patients should be supported to make informed decisions regarding their treatment and ‘consent’, as defined in Section 56 relating to consent to treatment, should include consent given by a patient with the support of a family member, friend or an appointed ‘carer’, ‘advocate’ or a support decision maker appointed under the proposed capacity legislation”.
- 11.2. When working with Deaf patients, staff should be made aware, through their Deaf Awareness Training, that specialist advocacy services are available and the client should be informed of this accordingly. All accommodation possible should be made in this regard. The Irish Deaf Society runs a professional Advocacy Service.
- 11.3. It is vital in the case of ‘carer’ or ‘advocate’ being used that the Deaf person is encouraged to act autonomously with the support provided, rather than have someone make the decisions for them.

12. Information and individual care/recovery planning

- 12.1. The development of specialist in-patient facilities and services catered to d/Deaf patients could mean that some of the problems encountered by /Deaf patients could be avoided.
- 12.2. Research shows that the Irish Deaf community are at a higher risk of suffering from mental health issues than their peers because of many factors including marginalisation, the oral education system and historical institutional abuse. Despite the research proving that this cohort of people has a need for specialised access to mental health services, the access has not been granted.
- 12.3. Some mental health providers mistakenly assume that they can deny services to disabled people due to the lack of expertise of staff, lack of funds for providing accommodations, or inaccessibility of their facility.



- 12.4. The HSE has assumed operation of mental health services for the Deaf community which was managed by Chime at one point. As we understand it the HSE has appointed a Psychiatrist in Oct 2019 to provide services to the Deaf Community. However, they have provided feedback that, without an appointment of supporting roles, they are not in a position to take referrals. This service has recently been restarted but was insufficient in meeting the demand in the previous years. The Mental Health and Deafness service must be available nationwide.
- 12.5. IDS are particularly concerned that the economic difficulties and potential for waves of Covid-19 in the near future will result in a spike of mental health issues in the general population and marginalised communities like ours. We anticipate the need yet again to campaign for equal access to information and services.
- 12.6. In 2015, DeafHear reported a lack of appropriate residential services for Deaf people. It was found that there were more than ten Deaf people with mental health difficulties in mental health residential services around the country, with no access to communication in their daily lives and no rehabilitation supports.

13. Inspection, regulation and registration of mental health services

The Irish Deaf Society do not currently have any comments to make under this heading.

14. Provisions related to children

- 14.1. On page 70 of the report, we look at provisions related to Children. The majority of Deaf children are born to hearing families and often experience language barriers which can create difficulties with age-appropriate language development.
- 14.2. This in turn can lead to social, educational psychological and emotional issues which need to be considered when working with a Deaf person regardless of the age they are at when availing of the service.
- 14.3. Research shows that deaf children have an increased incidence of mental health problems compared with hearing children. There is an urgent need for a nationally available Mental Health and Deafness Child and Adolescent service.

15. Provisions related to the Mental Health Commission

The Irish Deaf Society do not currently have any comments to make under this heading.



Conclusion

In summary, the Irish Deaf Society, in their capacity as representative of the Deaf Community in Ireland, strongly endorse the recommendations of the Expert Group Review as they pertain to the promotion of fair and equitable treatment of clients whilst engaging with Mental Health Services.

For Deaf people engaging with hearing society in general, communication can be a struggle and this can lead to misunderstanding and misinformation. In the realm of Mental Health Services such misunderstanding and misinformation, if allowed to happen, can have serious and devastating consequences for Deaf clients. This is unacceptable.

In 2017, the Mental Health Reform submission on review of 'A Vision for Change' put forward a number of recommendations and actions that were related to Deaf people. While the actions linked to ISL Interpretation have been acted on as a result of the passing of the ISL Act, the actions relating to appropriate awareness and accessibility have not yet been met. Throughout the document we have highlighted the importance of the necessary training for professionals working with Deaf people, and this needs to be a priority in the updating of the Mental Health Act. The New Mental Health Act should enshrine in law provisions for Deaf Awareness Training within mental health services, both public and private, and commit to further provision of interpreter and advocacy services for Deaf patients/service users.

The Expert Group posited Guiding Principles that should be specified in the new law: autonomy, self-determination and dignity. The Irish Deaf Society believes these principles should underpin all interaction with Deaf patients and this is best achieved through overcoming communication barriers by way of provision of interpreters, and evolving attitudes through Deaf Awareness Training and collaborative working with appropriately developed specialist Mental Health and Deafness services.

We fully agree with the Expert Groups' emphasis on people's right to information, including information about treatments, awareness of complaints mechanism, consent or refusal of treatment, and the issue of "institutional influence". These factors combined are rooted in communication between mental health staff and the client and the IDS submits that the New Mental Health Act should incorporate accommodations specifically for Deaf patients in order to optimize said communication.



Appendices

Appendix 1

Supporting Information and Documents

1. Mental Health Reform Briefing note: Mental health services and supports for people who are Deaf, September 2015

https://www.mentalhealthreform.ie/wp-content/uploads/2018/05/Briefing-note-on-mental-health-services-for-deaf-people_-September-2015.pdf

2. Mental Health and Deafness by Margaret Du Feu and Cathy Chovaz, 2014
3. Mental Health Reform submission on review of A Vision For Change, 2017.

<https://www.mentalhealthreform.ie/wp-content/uploads/2017/09/Submission-on-review-of-A-Vision-for-Change.pdf>

4. Irish Sign Language Act, 2017

<http://www.irishstatutebook.ie/eli/2017/act/40/enacted/en/html>



Mental Health Statement and Action Plan

September 2020

Introduction

As Ireland's largest Deaf-led National representative organisation, the Irish Deaf Society (IDS) seeks to promote the equality and rights of Deaf people in Ireland. We work to provide better access to services and information for the Deaf community as well as the full inclusion of Deaf people in society. IDS seek to enhance the quality of living for all Deaf people who have limited employment and education opportunities which results in poverty for many. The Irish Government recognises that the Deaf community is consistently marginalised due to a lack of accessible information and services available in Irish Sign Language (ISL), the first and preferred language of the community.

Our Advocacy service clearly identifies a need for mental health services based on our one-to-one contact with clients presenting with a wide range of issues, concerns and complaints. A lack of accessible public and private services has led to an increase in depression, self-harm and suicide in the Deaf community.

Research shows that the Irish Deaf community are at a higher risk of suffering from mental health issues than their peers because of many factors including marginalisation, the oral education system and institutional abuse. Despite the research proving that this cohort of people has a need for access to mental health services, the access has not been granted.

The Irish Sign Language Act 2017 is to be implemented in December 2020 and this Act obliges public services to provide access services and information to Deaf people in their first language, Irish Sign Language. In 2018 Ireland ratified the United Nations Convention on the Rights for Persons with Disabilities which sets out minimum rights and entitlements for people with disabilities. Under Article 25 Ireland has committed to ensuring that people with disabilities



have access to the same range, quality and standard of free or affordable health services as others. This commitment is not being met.

For 12 years Chime ran a mental health service with CPN's and Margaret de Feu. Chime estimated that 50% or less Deaf people with mental health needs engaged with the service. In 2019 the HSE took over the running of this service and hired Dr. Xavier Fluvia on 9th October based on the North Circular Road, Dublin 7. Since that time a support team of Psychiatric Nurses have not been hired and it is unclear if services for Deaf people have officially commenced and we understand that no Deaf patients have been seen. It is a priority to ensure this service is fully operational and a clear referral process is in place and communicated to the Deaf community.

The Irish Deaf Society is developing a *Wellbeing and Mental Health Working Group* in order to represent our community and work with the State and healthcare providers to ensure these commitments are included in organisations strategies and action plans. Positive action has never been more urgent as Ireland and all of our communities respond to the Covid-19 pandemic.