ISL HEALTH Research Report

Key findings and recommendations from a project aiming to support the effective implementation of the Irish Sign Language Act 2017 in public healthcare settings.

Presented by research partners:

University College Cork (School of Applied Social Studies & ISS21)
Cork Deaf Association
Community K (formerly Kerry Deaf Resource Centre)
HSE's National Office for Human Rights and Equality Policy

September 2023

DEDICATION

This report is dedicated to the late Mr. Karol McGuirk, a highly respected member of the Deaf community who very sadly passed away in March 2022.

This dedication is a mark of appreciation for his tremendous contributions as an advocate for Irish Sign Language (ISL) awareness, an avid promoter of Deaf community interests and a highly skilled ISL teacher.

The ISL HEALTH research team hopes that the report will serve as a fitting tribute to his memory.

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ACKNOWLEDGEMENTS

The researchers convey their gratitude to the HSE Access Officers and ISL-English interpreters who generously gave of their time to share their professional observations on access provision in public healthcare settings for Deaf ISL users.

Sincere thanks are owed to the members of the Irish Deaf community who generously shared their views and experiences about accessing public bodies as part of the previous IHREC-funded project completed by this research team: (https://www.ucc.ie/en/iss21/researchprojects/researchprojects/earlieriss21projects/islaccesspublicbodies//) Those views and concerns provided the impetus for the ISL HEALTH research and were given primacy in the development of the project's objectives.

The ISL HEALTH Team gratefully acknowledges the funding awarded for this project under the Irish Research Council's New Foundations scheme.

The ISL HEALTH research project has provided a good opportunity to engage with the HSE's National Office for Human Rights and Equality Policy. Our thanks to Caoimhe Gleeson and Jacqueline Grogan for their support with the enactment of the research. It is hoped that the *ISL HEALTH* recommendations can be of value to the continuing work of that office with regard to the implementation of the ISL Act 2017.

Our appreciation is also extended to the following individuals and organisations:

- Dr Margaret Scanlon, Research Co-ordinator at the Institute for Social Science in the 21st Century, UCC, for her valued support over the course of the ISL HEALTH project:
- Council of Irish Sign Language Interpreters and the Register of Irish Sign Language Interpreters for their help and co-operation with distributing information about the project to interpreters.
- Catherine White and Suzanne Carey for the ISL-English interpretation provided over the course of the ISL HEALTH research project.

ABOUT THE RESEARCH TEAM

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Susan O'Callaghan is the Advocacy Officer at the Cork Deaf Association (CDA). She is Deaf and a native user of Irish Sign Language. Susan has worked at CDA for more than 20 years and has occupied different roles there during her career. Her work is now focused on community engagement with Deaf people throughout Cork city and county. As Advocacy Officer, Susan has a wide remit, supporting Deaf people at all stages of life (from infants to senior citizens) and in different circumstances, such as with mental health difficulties, working with Deaf people with intellectual disability and people who are deafblind. Susan is a qualified Deaf Interpreter. She also delivers Deaf Awareness Training.

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Consultative partners:

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Micheál Kelliher is a Deaf activist who was based in Dublin for many years and relocated to Kerry back in 2020. A software engineer and keen board gamer, Micheál has been on committees of regional, national and international Deaf organisations and working teams. He was one of the first Deaf persons in the history of Ireland to stand for elections.

1. INTRODUCTION: BACKGROUND, RATIONALE & AIM OF THE RESEARCH

The *ISL HEALTH* research team takes the position that any research relating to matters of concern to the Irish Deaf Community should give primacy to the views and concerns of community members. The *ISL HEALTH* project builds on a previous study carried out collaboratively by UCC, Cork Deaf Association and Community K (formerly Kerry Deaf Resource Centre). Funded by the Irish Human Rights and Equality Commission (IHREC), that project[1] produced **Guidance for Public Bodies on Providing Access for Deaf Irish Sign Language Users[2]** (a copy is provided as an appendix to this report). The IHREC-funded study entailed a national consultation with members of the Irish Deaf community to ascertain their views, experiences and concerns about access provision by public sector bodies. Among the responses received, issues relating to public healthcare emerged as a dominant concern. It was on that basis that the ISL HEALTH project was developed.

In the Republic of Ireland, the issue of accessibility to public health services for deaf people has been explored in research and policy contexts [including Medisigns research project (2010-2012), Citizens Information Board (2018) and the National Disability Authority (2012)], while issues relating specifically to engagement with deaf patients and sign language interpretation are considered in the HSE's *On Speaking Terms* policy and the *National Guidelines on Accessible Health and Social Care Services* (2016) which, significantly, were developed prior to the passing of the Irish Sign Language (ISL) Act (2017) into law. Citizens Information Board (2018) reported that a combined total of 73% of respondents to its survey exploring information provision and access to public and social services for the Deaf community, indicated that access to HSE services (including hospitals, primary care centres and GPs) was either poor or very poor. This was further corroborated by the first-hand experiences, views and concerns of Deaf community members which were gathered as part of the IHREC-funded project (2021) which explored access provision by public sector bodies generally. We understand from existing research that persistent access issues in public healthcare include, but are not limited to, inadequate provision of sign language interpretation; audist attitudes of public service providers; inconsistencies in access provision for deaf

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[1] https://www.ucc.ie/en/iss21/researchprojects/researchprojects/earlieriss21projects/islaccesspublicbodies//

[2] Available to download here:
https://www.ucc.ie/en/media/research/iss21/GuidanceforPublicBodiesonAccessProvisionforDeafISLUsers.pdf

service users; and the discriminatory effects of hearing privilege which is deeply embedded in public systems of communication.

In order to eradicate these forms of disadvantage from public health systems, is important to first fully understand audist systems and practices which privilege hearing ways of being, so that we are better placed to dismantle them. Public bodies need support with this process. As indicated on the HSE website[3]:

> “There are gaps in the way that we provide some services, and it is fact that some of our facilities are not easily accessible to those with disabilities. Access Officers will help us systematically work to address these gaps and ensure that future services and facilities […] are fully accessible to everyone”.

This provided the impetus for collaborating with the HSE’s National Office for Human Rights and Equality Policy as a consultative partner on this project and it is hoped that the findings herein can support that Office’s work as it continues to monitor the implementation of the Irish Sign Language Act 2017 across the organisation.

Given the importance of timely access to appropriately skilled interpretation for sign language users, it was decided to also collect the professional observations of that cohort on the topic of access provision.

Aim and objectives of *ISL HEALTH* Project

The overall **aim** of the *ISL HEALTH* project is to acquire the knowledge, views and experiences of HSE Access Officers[4] and ISL Interpreters on matters pertaining to the provision of access to public healthcare settings for deaf Irish Sign Language users. This aim serves the purpose of helping us to understand the persistent gap between best practice standards and the inconsistent access provision which has been widely and repeatedly reported by Irish Sign Language users in public health services, and to identify strategies to support public

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[3] https://www.hse.ie/eng/services/yourhealthservice/access/accessofficers/

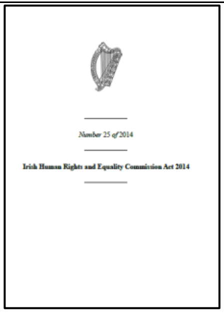
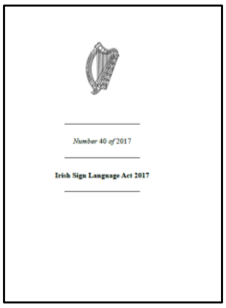
[4] Disability Act 2005 Section 26 (2) provides that ‘Each head of a public body referred to in *subsection (1)* shall authorise at least one of his or her officers (referred to in this Act as “access officers”) to provide or arrange for and co-ordinate the provision of assistance and guidance to persons with disabilities in accessing its services.’

healthcare providers to fulfil their public sector duty obligations, thereby working to eliminate the discrimination too often experienced by members of the Deaf community.

The **objectives** of the project are as follows:

1. To ascertain the levels of awareness among HSE Access Officers of the standards enshrined in the ISL Act 2017 and the associated public sector duty.
2. To examine the perceived challenges associated with implementing the legislation.
3. To explore the potential for procedural innovation to support the HSE towards fulfilment of its public sector duty in accordance with the Act.

Legislative and policy context – key considerations for the *ISL HEALTH* Project

3 GOOD HEALTH AND WELL-BEING	**United Nations Sustainable Development Goals** Goal 3[5]: Ensure healthy lives and promote well-being for all at all ages
CRPD CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES	**Article 21 Freedom of expression and opinion, and access to information** **(e)** Recognising and promoting the use of sign languages. **Article 25** States Parties recognise that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. **Article 33 National Implementation and Monitoring** **Article 33(3)** Civil society, in particular persons with disabilities and their representative organisations, shall be involved and participate fully in the monitoring process. While Ireland ratified the UNCRPD in March 2018, it has not yet ratified the Optional Protocol to the UNCRPD; this means that the Irish government does not yet 'agree to recognise the competence of the Committee on the Rights of Persons with Disabilities to consider complaints from individuals or groups who claim their rights under the Convention have been violated'[6]
 *Number 25 of 2014* Irish Human Rights and Equality Commission Act 2014  *Number 40 of 2017* Irish Sign Language Act 2017	**Public sector duty, as per:** **Irish Sign Language Act 2017[7] (Section 6)** **Irish Human Rights and Equality Act 2014[8] (Section 42)** In accordance with Section 10 of the ISL Act 2017, The National Disability Authority was tasked by the Minister for Children, Equality, Disability, Integration and Youth to prepare a report on the operation of the Act. In its report of December 2021, the NDA stated that 'health is among the key services that attracted public feedback about inadequacies to access through ISL' (NDA, 2021: 16).

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[5] https://sdgs.un.org/goals/goal3

[6] https://nda.ie/disability-policy/uncrpd#:~:text=States%20Parties%20may%20opt%20out,Optional%20Protocol%20to%20the%20UNCRPD

[7] https://www.irishstatutebook.ie/eli/2017/act/40/enacted/en/html

[8] https://www.irishstatutebook.ie/eli/2014/act/25/enacted/en/html

2. ACCESS TO HEALTH INFORMATION AND SERVICES FOR DEAF PEOPLE: A LITERATURE REVIEW

1. Introduction

International evidence indicates that sign language users experience inequalities and disparities when accessing public health systems, as compared against their hearing peers. Writing in the UK context, Alexander, Ladd and Powell (2012) highlight barriers arising from poor communication and low deaf awareness levels among healthcare professionals, with the authors asserting that ‘ignorance leads to negative attitudes, and patients from the Deaf community endure both individual and institutional discrimination.’ In the same jurisdiction, SignHealth (2014) reported that just over 1% of videos on the NHS Choices website are in sign language. Barnett et al’s (2011) research concluded that Deaf people who use American Sign Language are ‘medically underserved’, while in the New Zealand context, Witko et al (2017) have noted that ‘accessing healthcare services, understanding information and interacting with healthcare personnel is problematic for many deaf New Zealand Sign Language users, partly due to health literacy and English literacy disadvantages, as well as a lack of provision for communication in their preferred modality.’ It is clear that these are global challenges.

As is the case in many other countries around the world, health services in Ireland have undergone considerable change in response to international demands for more equitable health care information and health services for people with disabilities. Increasingly, health service providers are being called upon to consider how they might address the needs of service users in a manner that recognises equal rights and inclusion for all, however, deaf people as a community remain one of the most marginalised groups in Irish society (Linehan, et al., 2014; Martin and McDevitt 2017; IHREC, 2020; UNCRPD, 2006; WHO, 2021). Within recent decades, there have been a series of significant government-sponsored reports highlighting the inadequacies of health service provisions for people with disabilities in Ireland (HSE, 2017; IHREC, 2020; NDA, 2020), and the barriers to accessing relevant health care information and health services faced by members of the Irish deaf community (Martin and McDevitt 2017; IHREC, 2020; O’Connor and Harold 2021). Researchers during this period have endeavoured to understand how deaf people experience inclusion and equity of access to health services. The World Health Organisation (WHO) defines “accessibility” (physical and economic access, together with access to information) as one of the four elements of the right to health care (WHO, 2007, p.1-2).

This review addresses the Irish situation but also includes the wider international literature on access to health information and health services for deaf people. The nature of the review is dictated by the end users themselves, namely the Irish deaf community and health service providers in Ireland. The purpose of this review is to place the research within the context of literature on access to healthcare services for deaf communities in Ireland and abroad. The review is used to identify gaps in knowledge and gaps in health best practice standards regarding access provision for deaf people in public health services. The review used standard data bases such as Google Scholar and BASE in order to identify literature that address issues related to "healthcare provision," "healthcare access for deaf people," "health policy and disability," and "health service and sign language." From these sources, literature was sorted and categorised into common themes. Papers and texts and policy papers were identified that address issues around the provision of and support for health care in deaf communities, and relevant literature in the field of deaf studies were also included in the review. This allowed the researchers to analyse public policy in Ireland with a focus on the Irish deaf community. Though this process, it was possible to gain a more detailed picture of public health service provision and practice in Ireland. Furthermore, themes were identified in the international literature that have not been addressed in an Irish context.

The structured approach to the review as outlined above resulted in three key themes within which the literature was categorised: policy and legislation; key challenges to accessing healthcare; and key approaches to improving access to health services. A number of subthemes emerged from these, such as barriers to health literacy, factors that impede access to healthcare, barriers to mental health services, provision of sign language interpretation, and access to health care centres for deaf people, as well as discussions about how such barriers can be overcome by education and training. This approach allowed the researchers to present key themes from the international literature and to identify gaps in health knowledge and health service provisions in Ireland. This review provides a possible foundation from which to conduct further systematic analysis of literature within the context of ISL, health and deaf people.

2. Policy and Legislation

The Irish Government's ratification of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (UNCRPD, 2006) in March 2018 places a strong emphasis on participation and inclusion. The

implication of ratification is that the Irish Government now acknowledge that the UN's guiding principles need to be implemented into its national legislation and policies. A key principle of the UNCRPD (2006) is the notion of "accessibility," which Broderick (2020) defines as "the inclusive practice of removing barriers to ensure equal access for persons with disabilities to, among others, built environments, goods and services, as well as facilities" (p.393). Broderick further notes that Article 9 UN-CRPD requires state parties and the private sector to consider accessibility issues as part of their obligations to provide appropriate resources to people with disabilities. The enactment of the Irish Sign Language (ISL) Act 2017, which commenced in December 2020, seems to support this idea in relation to deaf people (O'Connell 2021). As Conama (2021) points out, the Act contains 11 clauses covering the right of deaf people to use ISL as their native language and the obligation on public bodies, including the Health Service Executive (HSE) and local health authorities, to provide free access to ISL interpretation when availing of public services. The duty of public bodies in relation to the Act is the provision of ISL interpretation at no cost to the ISL user. According to O'Connell and Lynch (2021), the ISL Act emphasises the importance of setting up of an accreditation and registration scheme for ISL interpreters and the establishment of a national register of ISL interpreters. This means that public bodies and the courts of law are required to engage professionally trained and qualified ISL interpreters who are members of the Register of Irish Sign Language Interpreters (RISLI), a national voluntary group tasked with maintaining a register of ISL interpreters.

The literature related to sign language legislation tends to be focused on the route toward enactment of the sign language act, with little insight offered on implementation. As Conama (2020) demonstrates, the ISL Act 2017 requires the government to produce a review report three years after enactment and every five years thereafter (Government of Ireland, 2017, p.6). The author notes that such a review mechanism is largely unavailable in most European countries that have their national sign language legally recognised. While this puts Ireland in a more favourable light, Scotland appear to have made significant strides in the implementation of the British Sign Language (BSL) Act 2015 (Lawson, et al., 2019). For instance, the BSL (Scotland) Act 2015 has a dedicated BSL National Plan 2017-2023 devised by BSL National Advisory Group (NAG) comprising of deaf and deafblind people and representatives of public bodies. As McCallion (2020) reports, the BSL National Plan includes ten key long-term goals and 70 key actions to be undertaken by the Scottish Ministers. The public bodies that Scottish Ministers have responsibility for are required to develop their own BSL National Plan dedicated to improving the quality of life of BSL users in Scotland covering education, employment, health,

mental health and wellbeing, transport, culture and the arts, justice and democracy (Lawson, et al., 2019). Further to this, public bodies are required to publish BSL Action plans every six years setting out how they will support BSL users accessing these services (McCallion, 2020). The significance of this requirement as social policy is that it provides public bodies with a clear guideline and structure for implementing the BSL (Scotland) Act 2015. This strategy might prove useful in an Irish context, as Ireland currently has no ISL national plan in place, and public bodies do not have the responsibility for managing and publishing their own ISL plan (Conama, 2020). This might explain the lack of awareness or clarity among public health service providers around their obligations in accordance with the ISL Act 2017 (O’Connor and Harold, 2021).

3. Key Challenges to Accessing Healthcare

Just as deaf people have the same health needs as every other member of the population, they also have the same rights to access healthcare as hearing people. Yet, as Kuenburg, et al. (2016) report, deaf people face persistent barriers in accessing healthcare, health information and other health service provisions due to a number of factors including difficulties communicating with healthcare professionals and staff, lack of awareness amongst health staff members of the cultural and linguistic needs of deaf people, and the limited English language literacy affecting some members of the deaf community.

3.1 Barriers to health literacy

Discussions centred around healthcare provisions for deaf people tend to have concentrated attention on limited access to communication based on speech and auditory skills, a debate that has been an ever-present topic for research internationally (Kuenburg, Fellinger and Fellinger, 2016). One of the most pertinent communication barriers reported in the literature is the low literacy levels among the deaf population. It is clear from the research that deaf people experience literacy problems (Dammeyer 2014; Mathews and O’Donnell 2020). Low literacy levels have particularly affected deaf children who were taught via school programme of oralism which prohibited them from using sign language (Anglin-Jaffe, 2013, 2015). Reporting on a survey on literacy standards among the deaf population in England, Conrad (1979) found a troubling link exists between literacy failure and oralism. Oralism is an educational ideology promoting the belief that deaf children should be taught exclusively through the medium of spoken language (e.g., English) and that it is better for them to learn to speak than to sign (O'Connell and Deegan 2014). Conrad's main hypothesis was that deaf children may not be able to read if internal cognitive processing occurred through speech. The results of his research indicated one conclusion: that the average reading age of 16-year-old deaf school-leavers was similar to the level attained by 9-year-old hearing children. In Ireland, similar outcomes were reported in James, O'Neill and Smyth's (1991) study on the national testing of Irish deaf school children (cited in Mathews and O'Donnell 2020). Using Conrad's testing procedures, the researchers assessed the reading comprehension of 358 deaf children selected from schools for deaf children in Dublin. The study concluded that 16-year-old deaf children had, on average, a reading age of 9.2 years. However, no such research on the reading outcomes of deaf children had been conducted in Ireland until Mathews and O'Donnell (2020) surveyed a sample of deaf children attending mainstream schools where they were exposed to spoken language throughout their schooling. The authors conducted reading assessments to measure the skills of phonological decoding and reading comprehension of deaf children aged between 7 and 13 years. They conclude that, while deaf children's phonological skills improve over time, their reading comprehension gradually fall behind their hearing peers. There is some evidence that the concerns expressed by Conrad (1979) are being reported in other countries (Dammeyer 2014), which indicate that literacy problems among deaf people is widespread.

McKee at al. (2019) argue that health literacy for deaf people is crucial for making appropriate health-related decisions and treatment choices. The researchers of this study found that deaf people are more likely than hearing people to use the internet to seek health information despite having inadequate health literacy themselves. Naseribooriabadi et al. (2017) report that deaf people requiring health services find themselves embroiled in a struggle to understand printed health information, which places them at serious disadvantage in terms of access, with implications for health outcomes. Witko et al. (2017) found that deaf people who struggled to read health brochures, leaflets and instructions often rely on friends and family members to explain written material. The researchers report that deaf people mentioned gaps in their health literacy and English language literacy indicating a need for health information to be made accessible through the medium of sign language.

3.2 Other factors impeding access to healthcare

Besides the barrier of literacy problems, the negative attitude of health service providers towards deaf people is frequently emphasised in the literature. According to Cooper at al. (2004), this occurs directly as discrimination or unfriendly behaviour and indirectly through ignorance, fears and prejudices. The researchers found that health service professionals tend to exhibit a range of negative attitudes and behaviours toward deaf people. These include the expressed belief that deaf couples should receive genetic counselling to avoid having deaf children and that deaf children should learn to speak rather than sign. In a qualitative study of deaf people from the National Institute for the Deaf in Worcester, South Africa, Kritzinger et al. (2014) found that deaf people do not receive sufficient support from healthcare professionals who exhibit harmful and discouraging attitudes towards them. Some of the barriers identified in this study include disrespectful treatment and being denied health information because health service providers felt uncomfortable about communicating with deaf people. There is also an assumption among health service providers that deaf people can understand information or get by through lipreading. Kritzinger et al. (2014) suggest that health professionals are generally unprepared to provide medical care for deaf patients and do not know how to meet their cultural and linguistic needs. They spend less time explaining the medical diagnosis or treatment than they do with hearing patients. Furthermore, it was found that health professionals are not sufficiently trained to deal with the presence of a sign language interpreter during a medical appointment with a deaf patient. As highlighted by Kritzinger et al. (2014), negative attitude towards and perspectives on deafness have an impact on deaf people's participation in health service provision. The consequences include fear, frustration and mistrust of health services. In that context, deaf people may refrain from asking questions about their medical condition or treatment and end up feeling there is nothing of value to discuss. As the researchers observe, deaf people may leave the health service with little or no idea about the diagnosis and medical treatment received from health professionals.

The views expressed by Kritzinger et al. (2014) are confirmed by Witko et al. (2017), who considered sensory barriers to be a significant concern for deaf people. Witko et al. conducted focus group and individual interviews with 56 deaf people including their family members about their experiences of healthcare services which indicated that the institutional system privileged the audiological needs of hearing people and disadvantaged deaf people. In particular, managing health appointments presents a significant challenge for deaf people because health services often provide a landline phone number as their only point of contact. The only way deaf people could make or change an appointment was to use mobile text or email, but these contact

alternatives are rarely available in healthcare settings. Another sensory barrier highlighted by Witko et al. (2017) is the requirement to speak and hear through an intercom to enter a health centre or hospital, which causes delays in meeting the appointment time. The medical waiting rooms generally do not provide visual alert systems for deaf people who then must keep a constant watch on the reception area and try to discern when their name is being called. Deaf people describe incidents where they had missed their turn in the waiting room, despite asking the reception staff to alert them when their names were called because they wouldn’t be able to hear.

3.4 Barriers to accessing mental health services

The literature pertaining to mental health and deafness has established that deaf people have a higher rate of mental illness in comparison to the general population (Recio-Barbero et al., 2020). Although exact figures are difficult to ascertain due to a lack of research on the subject, deaf people are exposed to more mental health risk factors compared to hearing people and this problem is quite likely to be prevalent among the deaf population in Ireland and elsewhere around the world (Du Feu and Chovaz, 2014; Levine 2014). Deaf people are susceptible to experiencing mental illness due to a number of factors including social isolation, communication barriers, low literacy skills, poor educational achievements, institutional abuse, unemployment, and deafness stigma (Recio-Barbero et al. 2020; Mousley and Chaudoir, 2018). Another contributing factor is that approximately 90% of deaf children are born to hearing parents and have little or no access to sign language during their formative years (Mitchell and Karchmer 2004). In some cases, the delay in acquiring language correlates with mental health issues for (Fellinger et al. 2012). While many deaf people need mental health provisions at some point in their lives, they have poorer access to these services because mental health professionals lack the required knowledge and skills to work with them (Recio-Barbero et al., 2020).

In Ireland, the provision of mental health services for deaf people remains underdeveloped when compared to services for the general population (Du Feu and Chovaz, 2014). As Du Feu and Chovaz note, deaf people in Ireland and the UK have had to rely on “mainstream” mental health systems and, as a result, are more likely to encounter difficulties with accessing services because professionals and staff do not have sufficient knowledge and skills to work with them. Ramsay and Dodd (2018) identify the Department of Health as responsible for providing strategic leadership to public health services in Ireland while the Health Service

Executive (HSE) looks after the operation of mental health services to people with disabilities. The authors noted that both the HSE and voluntary and independent sector agencies provide mental health services for people with disabilities in Ireland.

4. Key Approaches to Improving Access to Health Services

The literature pertaining to the health and well-being of deaf people has attempted to show a number of ways to ensure optimal access to health services. Recommendations include the provision of deaf cultural awareness training for medical professionals and staff, an acknowledgement that deaf service users are best placed to provide unique insights into health service provision,

and the key role that sign language interpretation plays in breaking down barriers to accessing health services.

4.1 Education and training

Kuenburg at al. (2016) suggest that education and training courses in deaf culture should be provided to medical students and professionals for improved health service accessibility. The authors suggest that education in deaf culture will improve communication between medical professionals and deaf people. As Witko et al. (2017) emphasise, the prevalence of negative attitudes and lack of deaf awareness on the part of health professionals underscore the need for such training in medical schools. In their study, the majority of deaf people felt that health professionals who exhibit little or no deaf cultural awareness often demonstrate explicit and implicit negative attitudes towards them as patients. The authors report that medical schools do not provide their students with the required training to communicate with deaf patients. Without appropriate training in deaf culture, the authors point out, deaf people will continue to experience communication barriers and face negative assumptions about them. To emphasise the importance of education and training in deaf culture, Witko et al. (2017) provide an example of how this can transpire: they report that health service professionals assumed that when a deaf patient cannot answer questions in print form that he or she may have an intellectual disability. Some professionals may not know about the literacy problems affecting the deaf population, but others may assume that deaf people can understand medical information simply by reading printed material

(McGlade, et al., 2013). Witko et al. (2017) suggest that these instances underscore the need for better medical training to serve the cultural and linguistic needs of deaf patients.

As discussions around the importance of medical training in deaf culture and optimal access to health service provisions have developed, there is some evidence that sign language courses have been provided to medical students. For instance, British Sign Language (BSL) and Deaf Awareness curricula have been delivered to second year medical students at Queen’s University Belfast (QUB) in Northern Ireland (McGlade and Woodside 2012). As McGlade and Woodside report, the course was designed in conjunction with Action on Hearing Loss and QUB medical educators and consisted of three-hour British Sign Language (BSL) classes, deaf awareness sessions and an online BSL Medical Dictionary being made available to all medical students. The module was delivered for a 12-week semester, at the end of which students completed the Signature ‘Introduction to BSL Healthcare Level 101’ examination. McGlade at al. (2013) suggest that such training can lead to broader equality in healthcare for deaf people. Approximately two thirds of universities in Ireland and the UK have offered such training courses but these vary in terms of design and format and number of medical students in attendance (Gilmore et al., 2019; McGlade et al., 2013). The IHREC-funded study (2021) which produced Guidance for Public Bodies on Access Provision for deaf ISL Users (2021) recommends that explicit guidance on deaf awareness education should be made available to staff in public bodies, including healthcare settings.

4.2 Access to health services through sign Language interpretation

An increase in the number of specialist sign language interpreters working in medical settings has been reported internationally (Olson and Swabey, 2017; Schniedewind, Lindsay and Snow 2020). In many countries, research on the role of sign language interpreters working in medical settings has focused on direct access to health services for deaf people. Often, as is the case in Ireland, this includes studies showing how the sign language interpreter engages in interpreting activities that meet the complex demands of healthcare settings (Metzger, 2014). As Metzger emphasises, sign interpreters working in medical settings need to be familiar with clinic-specific knowledge and to possess sufficient linguistic skills for interpreting tasks to enable medical professional and deaf patient communicate with each other. Fellinger et al. (2012) has suggested that the role of professional sign language interpreters is being shaped by demands for accessibility and increased inclusion. O’Connell and

Lynch (2021) identified a commitment to professional development from both deaf and hearing interpreters in Ireland. They suggest that increased opportunities for accreditation and career enhancement for ISL interpreters has proved beneficial to the equal access and inclusion agenda. O'Connell and Lynch maintain that the primary function of a Professional ISL interpreter is to facilitate communication among deaf and hearing people in educational, health, legal, social, political, public and community settings. This process involves the hearing interpreter "hearing" the source spoken language message and delivering it in signed language and 'seeing' the signed message and delivering it in spoken language through simultaneous interpreting. If a deaf client uses idiosyncratic signs that are unrecognisable to the hearing sign language interpreter, a deaf interpreter may be engaged to work alongside the hearing interpreter (Boudreault, 2005). In this situation, the hearing interpreter hears the source spoken language message and translates it to sign language, and the deaf interpreter translates the message delivered in sign language into the signed language understood by the deaf client (Bentley-Sassaman and Dawson, 2012). As O'Connell and Lynch argue, this is to ensure accurate information about what a person has said is delivered to the individuals involved in the interaction, which is particularly crucial in a healthcare setting. Thus, improved access to health and mental health care can be achieved when professionally trained and qualified sign language interpreters are provided (De Meulder and Haualand, 2021).

4.3 Healthcare centre for deaf people

One of the major findings from Kuenburg et al. (2016) is the need for a collaborative system that allows deaf people access healthcare in an institution where staff members have the required level of knowledge in sign language and deaf culture. As the authors report, Austria is one of the first countries in Europe to establish a Health Centre for Deaf People, a unit attached to general hospitals where staff members are trained in deaf culture and have acquired a level of competency in sign language to communicate with deaf clients. Kuenburg et al. further notes that the role of these health centres has been shaped in a distinct manner that is focused on the healthcare needs of deaf people. Thus, it has become the primary health care facility for deaf people in Austria. The fact that the health centres are attached to the major hospitals means that deaf people can easily access a wide range of referrals and medical services from medical professionals and trained staff with the necessary skills to communicate with them. In the UK, while primary medical care to deaf persons is provided

by general practitioners or family physicians and National Health Services (NHS) Trusts (Ipsos MORI, 2013; Welton, n.d; Lam 2015), SignHealth has been established as a deaf health charity organisation to provide deaf people support in accessing a range of health services for deaf people in terms of psychological therapy, domestic abuse support, social care, advocacy and crisis text service. Opened in 1991, SignHealth operates through a partnership of NHS and other service providers, and the majority of its staff members are deaf people who engage in a variety of advocacy and campaign work to raise awareness of deaf people's health needs. The SignHealth initiative has resulted in an emerging set of guidelines and publications to guide healthcare delivery to ensure the quality of care and raise healthcare provider competence and confidence in providing appropriate, responsive healthcare to deaf people. (SignHealth 2014).

3. *ISL HEALTH* METHODOLOGY & ETHICS

The *ISL HEALTH* research team is cognisant that research fatigue is a critical concern among members of deaf communities. Given that a considerable amount of recent research evidence, both domestic and international, already exists and is telling us quite clearly that 'health needs among deaf populations globally remain unmet' (Kuenburg, Fellinger & Fellinger, 2016: 5), it was decided that the focus of the *ISL HEALTH* study would try to better understand the gaps in access provision in the Irish public healthcare context, and to explore the levels of Deaf awareness and understanding among those whose roles focus on access provision within the HSE. Foregrounding the view that members of the deaf community ought not to be disproportionately burdened with dismantling barriers not of their own making, the *ISL HEALTH* team took a 'study-up' approach, with a focus on systems of access provision and the individuals tasked with the responsibility of ensuring access.

The *ISL HEALTH* project methodology used a mixture of quantitative and qualitative methods. A total of eight ISL-English sign language interpreters, all of whom are hearing, responded to the invitation to participate in the project. Of those eight, three participated only in a focus group, three participated only in a one-to-one interview, while two interpreters participated in both a focus group and a one-to-one follow-up interview.

The research team provided advance notice of the survey to the access officer cohort and the survey, which was circulated via the HSE's National Office for Human Rights and Equality Policy, remained open for a three-month period, during which time several reminders were issued. Despite these measures, the survey response rate was very low, with just 19 responses received from a total cohort numbering approximately 200. It is therefore important to note that the survey data presented in Section 4 cannot be taken to be representative of the views of the full cohort. Of the 19 survey respondents, two access officers participated in in-depth follow up interviews with a member of the research team.

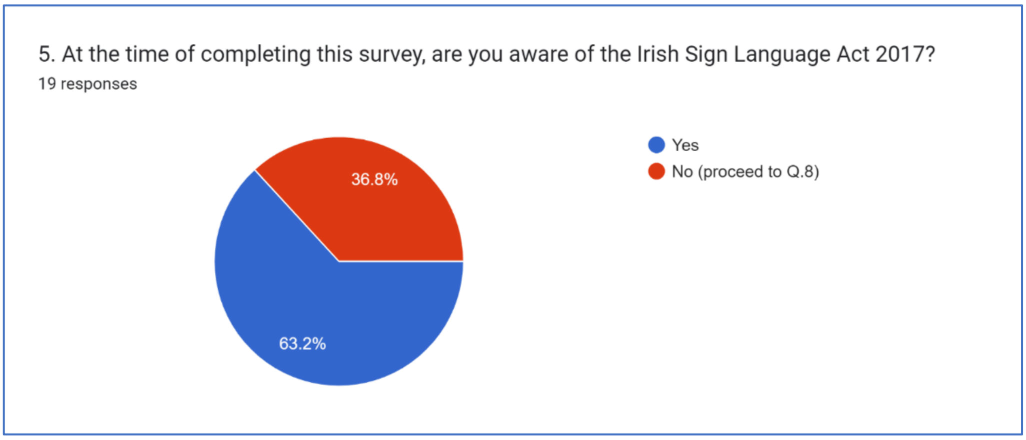
Ethical approval for this project was obtained from UCC's Social Research Ethics Committee and the HSE's Reference Research Ethics Committee for Midlands Area and Corporate Division (Regional Health Area B).

4. FINDINGS AND DISCUSSION

In this section of the report, we set out the main findings from the access officer and sign language interpreter cohorts. While certain themes were noted by both groups, many were of specific concern to one group or the other. Throughout this section, text that appears in italics in this section indicates that it is a direct quotation from a research participant.

ACCESS OFFICER PERSPECTIVES (FROM SURVEYS AND INTERVIEWS)

- Access officers are not universally aware of the ISL Act 2017 nor, by extension, its provisions.



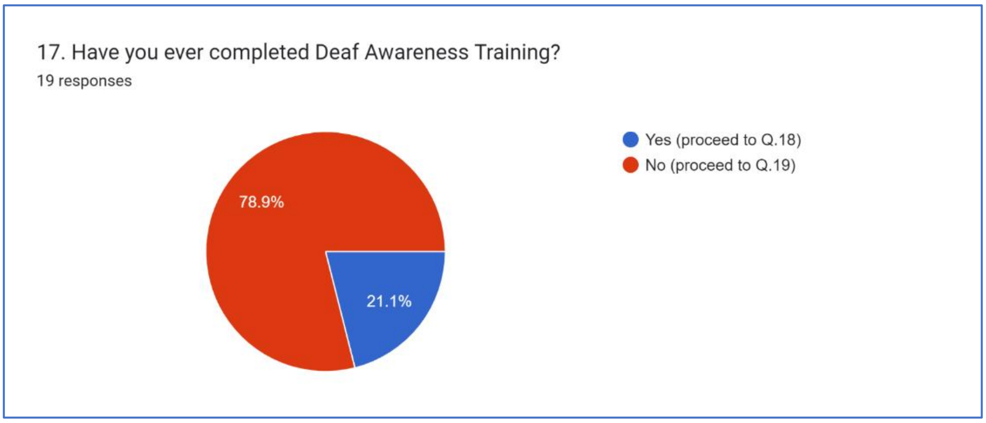
5. At the time of completing this survey, are you aware of the Irish Sign Language Act 2017?

19 responses

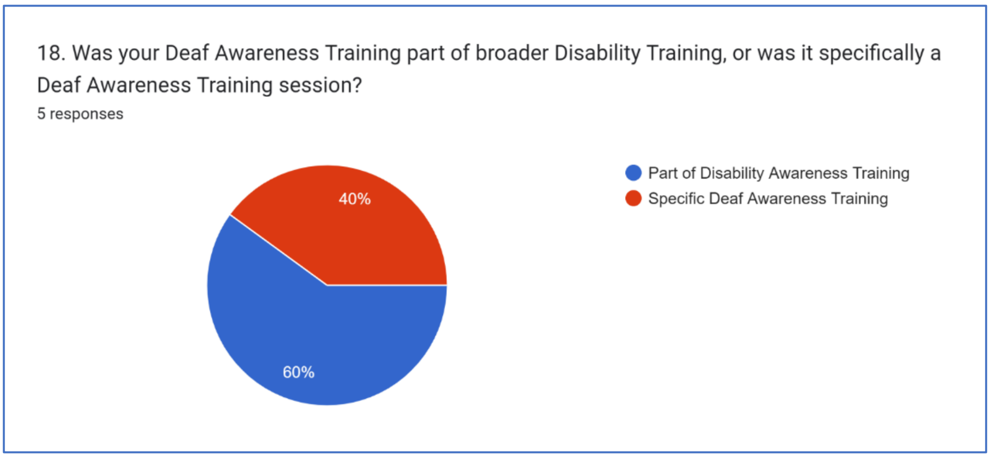
Where positive developments in access provision have been detected, these were often not related to the commencement of the ISL Act 2017, and instead related to existing policies including *On Speaking Terms* (HSE, 2009) and *National Guidelines on Accessible Health and Social Care Services* (HSE/NDA, 2016). Several interpreters similarly expressed the view that knowledge of the ISL Act 2017 among healthcare professionals is minimal. While all agree that it is hugely positive to have the Act as a further tool with which to lobby for improved access, there was broad consensus that its impact in positively effecting access provision to public health services has, as of yet, been minimal.

- Not all access officers have completed deaf awareness training. Among the respondents to the ISL HEALTH survey, 15 out of 19 indicated that they had not completed this training. Of those who had (n4),

in most cases it was part of a broader session of disability awareness training, rather than a discrete offering focused on deaf access issues.

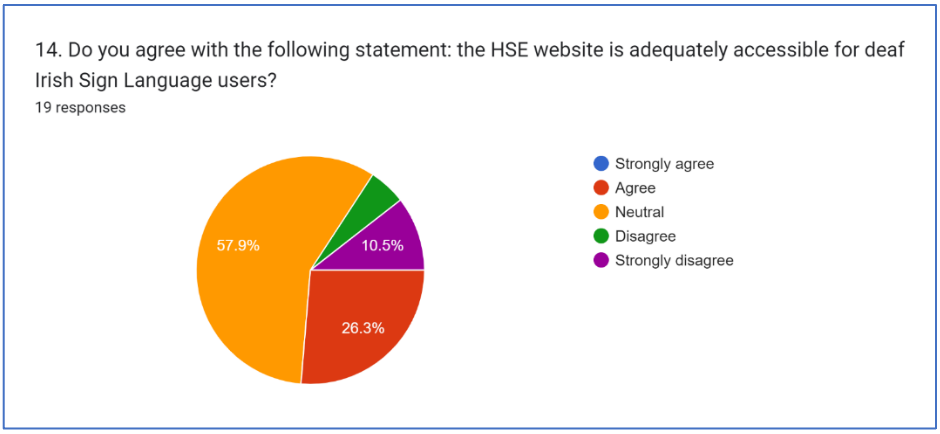


17. Have you ever completed Deaf Awareness Training?
19 responses



18. Was your Deaf Awareness Training part of broader Disability Training, or was it specifically a Deaf Awareness Training session?
5 responses

- It is recognised that the accessibility of the HSE website for deaf ISL users is not optimal.



14. Do you agree with the following statement: the HSE website is adequately accessible for deaf Irish Sign Language users?
19 responses

A cumulative total of 14 of the 19 survey responses indicated that they either disagreed with or held no opinion on the statement that the HSE website is adequately accessible for deaf ISL users. One of the survey respondents elaborated as follows:

Most of the HSE web information is only available in English, same with current switchboard options.

In line with many public health systems internationally, including in the UK where just over 1% of all videos on the NHS Choices website are in sign language (SignHealth, 2014), there is insufficient ISL information available on the HSE website and a lack of ISL versions of information sheets and consent forms. Blanck (2016) has written about the concept of ‘e-quality’ and argues that ‘*web content is king*, and full and equal access to it is crucial in all aspects of daily life’. With specific reference to ASL users, Blanck (2016: 175) explains that ‘some individuals may require ASL, or other sign languages not based in English grammar to aid in web content usability and comprehensibility.’ The issue of inaccessibility also extends to the preference for, and dominance of telephone numbers being provided as contact details, with email addresses and SMS text numbers being far less consistently available. This is problematic in terms of day-to-day procedural issues e.g., contacting a specific department to inform them of communication rights and requirements, but also in the context of meaningful feedback mechanisms. One of the Access Officers interviewed stated that, rather than only being able to receive feedback via formal complaints procedures, their preference would be as follows:

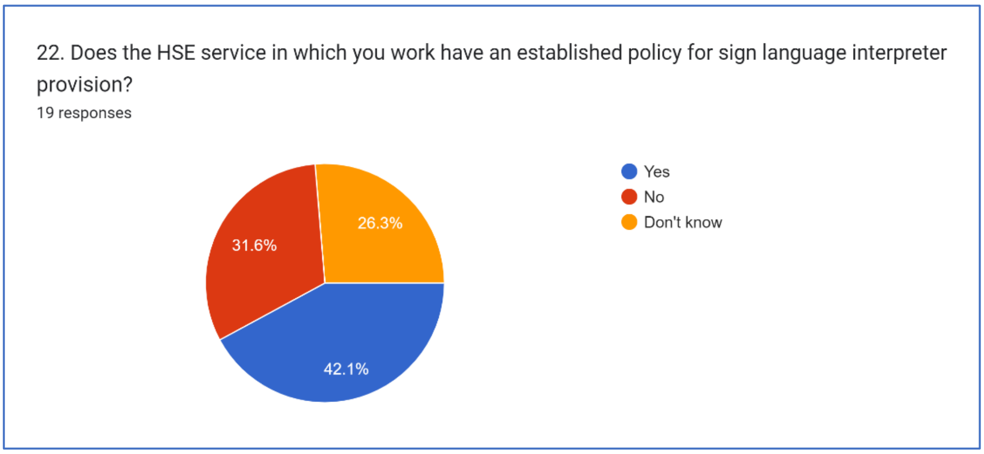
> *It is that kind of informal stuff that I prefer because it is […], you know, you were great, but this happened, and this is a learning point, or this is a […] teaching moment for your staff or whatever. So that's the stuff that we try to gather. We would then meet other access officers across all the programmes and try to see, look, what do we see in common? What do we maybe need to tackle? What do we need to go back to staff on?* (Access Officer 1)

For this type of interaction to be possible, it requires accessible channels of communication.

- Positive commitment to access provision is in evidence among access officers; this is not perceived merely as compliance, but rather as a response to genuine understanding of the value of increased accessibility for both staff and service users in public healthcare settings.

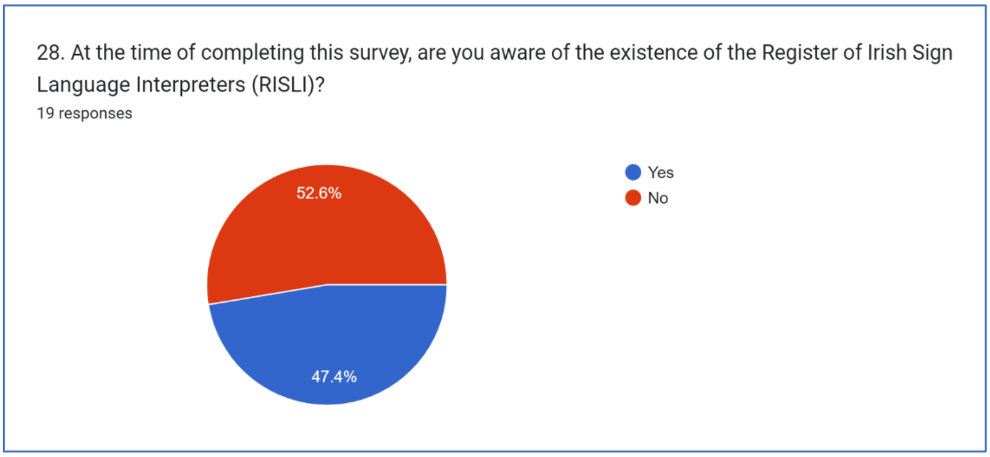
- Resource allocation is a structural challenge when it comes to ensuring access provision.

- Arrangements for booking and payment of interpreters are often ad hoc and vary across the CHOs.



22. Does the HSE service in which you work have an established policy for sign language interpreter provision?

19 responses



28. At the time of completing this survey, are you aware of the existence of the Register of Irish Sign Language Interpreters (RISLI)?

19 responses

- The ISL Act 2017 does not seem to have played a considerable role in informing the work of access officers or staff more generally. Access Officer 1, for instance, commented on being unaware of the nuances of the act: ‘*I’m probably touching on it by accident . . . in the work we do’.* Access Officer 2 expressed some positivity regarding the potential inherent in the Act:

> *I think there's a natural respect that maybe wasn't there before . . . ISL has been given legitimacy to anyone that had value in it. . . So, I think there's an openness to taking it on board and it probably just needs to be promoted like everything else you know and encouraged.* (Access Officer 2)

This same respondent pointed out that provisions of the Act must find expression on the ground to ensure that the legislation meets its full potential:

> *All the work has been done, but . . . [as] with any act and its implementation, it has to be driven out and maybe that's the piece that isn't happening yet. The Act is the vehicle, but someone needs to get into the car and drive it now, around the country.* (Access Officer 2)

The same participant went on to state that *'ISL isn't a health issue; it's a language'*, and as such it needs the protections that are afforded by political will and adequate society-wide resourcing.

- Access officers who participated in interviews signalled the challenge of ensuring consistent access provision across all public healthcare sites and expressed their concerns about a lack of standardisation:

  > *One of the problems that I've identified through the access officer role is: how do you ensure consistency for those four and a half thousand [primary care cervical screening] sites for all the women? . . . [How do] you ensure that there's consistency of provision of ISL interpreters for our deaf community accessing those services? (*Access Officer 1).

  Access Officer 2 commented that the HSE have 9 CHOs [Community Healthcare Organisations] that are akin to 'little empires – they all have their own emperor that makes the rules' – and this is seen as a barrier to ensuring consistency of approach to disabled service users across the entire health service: '*we are not good at making everything uniform*' (Access Officer 2).

- Access Officer 2 displayed awareness of the fact that each person may have individual needs, even within a differentiated group. For instance, reference is made to the need for tailored sign language communication for a particular service user, and points out the errors in making an assumption that there is a seamless set of needs across all sign language users and all members of the deaf community:

it's wider than [just sign language] . . . a lot of people have multiple issues and emotions and all that to go with it and that's the piece [that] has to be just considered.

- Reference was also made by Access Officer 2 to the insufficiency of signed content on HSE webpages, and of the potential for exclusion as a result: *there's no sign language interpretation of those videos . . . it's problematic when you're dealing with a narrow group, you can very easily leave them out, you know?*

- Access Officer 2 spoke to the difficulties in organising sign language training for staff members:

  > *So, we're encouraging to services to go off and do sign language training and usually you get all the staff are happy to get involved at the start and then it eventually withers down to one or two . . . [there needs to be] encouragement and promotion for people to engage in in embracing sign language and keeping it . . . it would have to be made, you know, more than just an add-on because add-ons fall away very quickly*.

- Access Officer 2 also commented on the specific need to risk assess interpreters who might be coming on board in a one-to-one situation, while also drawing attention to the problematic over-reliance on family members for interpretation;

  I suppose we get away with the sister or the daughter or you know, the son is with them, and they can speak, and they do it. So, I suppose that's how we're getting away with it at the minute. But what do you think of the dignity and of exercising someone's rights? We're nowhere near that.

- An interesting dichotomy between proactive and reactive approaches emerged over the course of both interviews. One access officer spoke of their role in identifying the reasons why users may not be participating in their services, and of their duty to ensure their services are as accessible as possible:

  > *we're always trying to figure out what might be the reason for that non-participation. Therefore, any accommodations that we can make to make our services more accessible, we try to pick them off one by one* (Access Officer 1).

  This is developed later in the same interview, where the access officer spoke to the need to understand the community and their barriers in order to fully understand why a certain intervention is being advocated for with regards to a particular community:

> *This is why we need to fight for this community . . . they have unusual barriers that we can't meet in other ways.*

Access Officer 2, meanwhile, commented that most of their work is reactive:

> *I'd say it probably is because most of our work is reactive. It's very rare that we're ahead of ourselves . . . you always operate with a bit of a squeeze on you all the time, be it finance, be it facilities, be it staffing . . . that's the baseline that you're working with, people that are slightly under a bit of pressure already and you're asking to take on a new challenge*.

- The need for ongoing development and improvement was flagged by Access Officer 1, who commented that awareness is what is needed to achieve sea change, and that the onus is on the providers of services to identify relevant barriers and to consider the ways in which these obstacles can be overcome to bring in service users. There is a clear correlation here between the need to improve access and corresponding improvements in uptake of a service: *what we need to do [are] service improvement projects which will bring in these communities.*

- The access officers pointed to the high value they place on feedback from service users. Access Officer 1 commented on interactions with the NDA and others: *asking them, you know, what do I do in this situation, or what is the best practice here? 'Your service, your say'.* Access Officer 1 also commented on learnings obtained from doing a gap analysis and needs assessment with service users including deaf people, with issues such as people not facing a deaf person when they are being called, best practice for using touch as a means of communication, and interactions with deaf people in general. Interestingly, the access officer concerned described this kind of interaction as '*a teaching moment for . . . staff'*, and so both feedback and complaints can be regarded as a learning opportunity for all.

- Reference was made to the issue of choice of interpreter by Access Officer 1, who commented on an uncertainty around whether a particular interpreter could be requested when follow-up appointments would need to be scheduled in another section of the health service. This was also picked up on by Access Officer 2, who comments that deaf service users *'don't even think that they have the choice … they bring the family member along.*

INTERPRETER PERSPECTIVES

- Many interpreters attributed any positive changes in access to ISL interpretation to the Covid pandemic as opposed to the passing of the ISL Act. For instance, Interpreter 1 commented:

  > *I do agree that there's certainly more awareness around ISL and provision, but I actually don't think it's because of the Act. I think it's because of the visibility through COVID that's primarily where I think it's come from.'* (Interpreter 1).

  Interpreter 2 maintained that the UNCRPD is more useful '*because that's more broadly known than the ISL Act',* but also spoke to the fact that recognition of ISL as a language did serve as a boost to deaf people in advocating for their rights to interpretation:

  > *Now I'm going to fight for all these rights that people have been talking about . . . I think for deaf people, it was that final, you know, "they finally recognised our language".*

  Interpreter 3 also picked up on this theme:

  > *I've seen a marked difference between people who would have always asked, requested and received access, and those who would probably would not have asked and then just got into habit and the pattern of not having access, who are now asking . . . they suddenly realised "I'm actually entitled to this, you know, and I will do whatever I can to get it".*

- Several interpreters spoke to an increased awareness of deaf issues as a result of the presence of ISL interpretation on public service announcements during the pandemic. Reference was also made to special provisions made for deaf people around mask wearing, with Interpreter 5 commenting of the greater awareness of the importance of facial expression and lip-reading: '*they were understanding of requests to remove masks from deaf people and interpreters.'*
- Issues were raised by some interpreters about the increased demand for their services as a result of the rights conferred on deaf people by the ISL Act: *my one fear . . . that we see coming true now . . . is that the demand is going to be so high'* (Interpreter 2).

- Interpreters were critical of some aspects of the provision of interpretation by hospitals. In general, a clear preference was expressed for dealing with an agency as opposed to dealing directly with hospitals.

The inconsistent approach to interpreter booking and payment across CHOs can result in a significant administrative burden for interpreters. This has the potential to disincentivise working in public healthcare settings, which applies even further pressure on an already chronic supply issue:

> *There are payment issues, delayed payments, withdrawn payments. It's not worth the hassle. I don't work independently* [i.e. not via agency referral] *with any of the public organisations, public hospital bodies, simply because of the red tape around it. I don't have the resources to be chasing minimal money that they delay in paying* (Interpreter 1).

- Several issues were raised pertaining to deaf clients’ ability to choose an interpreter of their preference. Oftentimes, it falls to the deaf client to request continuity of relationship with an interpreter, and the presence of the same interpreter across a number of appointments cannot be guaranteed: *if there is an ongoing situation where they are going once every three months or something, you will say yeah, I will do it for you unless I'm on holiday or whatever. . . sometimes they can be a year away . . . in which case you can phone the agency. . . you literally just have to phone them and say it's going to be another appointment in three months’ time (*Interpreter 3). In addition, questions are raised about the extent to which the deaf client is aware of their ability to choose an interpreter:

  > *Some deaf people will accept an interpreter because they're so delighted to have one that they really don't care as long as there's somebody there. There are some who know that they're entitled to choose and how they do that choosing . . . other than them saying to you at the end of the of the session, we got on very well. . .can you do the next one?* (Interpreter 3).

  Interpreter 1 flagged that the gender of the interpreter can sometimes be an issue, particularly with regard to appointments of a particularly intimate, invasive or sensitive nature while Interpreter 5 draws attention to the fundamental issue of low interpreter supply: *I think sometimes preference is a bit of a myth because there are so few of us in this country . . . you say to people “what's your preference?” but you know, often those interpreters aren't available.*

- Deviations in standards with regard to booking and paying interpreters across hospitals can be seen to result in poorer choice of interpreters for some patients. Reference was made to significant variation in

procedures from setting to setting, and sometimes even between departments in the same hospital: Interpreter 4 explained:

> *First of all, different departments in different hospitals seem to work with different agencies. So, if I'm working with one agency, and that deaf lady wants me to work again and it's in a different department, and that department is working with another agency who doesn't call me so … that can be a bit of a problem*.

Interpreter 3 reported a similar experience:

> *In [named regional hospital] a couple of the outpatient departments are amazing. Then you might have someone that's going in for a maternity appointment and there is a new administration person and they're like, 'I don't know what you're talking about, could you bring a friend?' So, the consistency of the message [is an issue]. We know that the message is there from the top, but it's not filtering down.*

- This problem becomes particularly acute when out of hours or emergency provision is required, with many deaf people having to resort to interpretation over the phone, with all of its attendant difficulties:

  > *'What can happen with out of hours is it becomes online . . . the doctors don't want to do it, or they don't have the facility, or the WIFI is dreadful . . . and it may be in an emergency that they'll have to facilitate with the deaf person's phone.'* (Interpreter 3).

  In addition, agencies may not necessarily handle an out-of-hours payment:

  > *The only place it becomes a problem is if it's late at night, this is emergency. . .you can accept it, but because you may not be able to get one of the agencies to take it over, it can be a complication. . . I've done one or two in the country and the hospital hadn't approved it, so I didn't get paid* (Interpreter 4).

  As stated above, this runs the risk of disincentivising interpreters from accepting work in these contexts, or at the very least narrows the pool of willing and available interpreters, with obvious adverse implications for deaf service users in these circumstances.

- Interpreter 5 commented that technology should not be viewed as a substitute for in-person interpretation*:*

> *'I would be concerned that people would miss information . . . something would be missing out of that conversation because people are caught up in the whole technology . . . and where do I look, and I can barely see you, and now you are in shadow'* (Interpreter 5*).*

The same interpreter developed this point by saying:

> *I do understand why deaf people [say] "I'm not waiting for an interpreter to be available. I want to see this doctor now and I want to talk to them now". My concern is that sometimes the powers that be go "oh, technology will solve everything and we'll just, uh, we'll video them in". Just not always appropriate.*

- Concerns were raised about access to interpretation across the entire duration of a hospital admission, with Interpreter 3 pointing out that a deaf person may have an interpreter present for formal admission and discharge but will revert back to 'pen and paper' for the duration of the actual hospital stay.

- Interpreters commented on the need for greater deaf awareness in healthcare settings, for instance, challenging the tendency of some healthcare providers to deliver medical information directly to the interpreter as opposed to engaging directly with the patient, having to remind the doctor to speak directly to the patient and not to the interpreter: '*there's only so many ways you can say to someone "can you speak directly to them please"?'* (Interpreter 2) or handing a prescription to the interpreter as opposed to the deaf patient: '*they hand it over to us, and you're just kind of, very discreetly. . . I haven't asked [the deaf person for permission to look at this]*' (Interpreter 3).

- Whilst interpreters acknowledged the benefit associated with family members being present at medical appointments to provide emotional support, concerns were raised about the potential for the autonomy of the deaf person to be undermined. For instance, Interpreter 5 spoke to situations where she was asked by hearing relatives not to interpret certain sensitive aspects of a medical conversation for fear of upsetting the deaf patient. That said, improvements were noted by the same interpreter whereby healthcare professionals demonstrate cognisance of the primacy of the deaf person's rights:

> *One of the big issues that I've always had … is hearing family members and their … interference in the care choices, plans, decisions of that deaf person. And it's done with very good intentions, but it is extremely disruptive. Now, more and more, I would see the professionals say "actually,*

> *no, this is not really about you. So do you mind stepping outside?” And I see that happening more where there's more autonomy given to the deaf person than there used to be it, and that is a really positive attitude shift that I've seen… That's not to say people still aren't patronising!*

- The provision of the GP Access Scheme was universally regarded as a positive development, with interpreters praising the efficiency of the service, and the attendant increased awareness of deaf issues. For instance, Interpreter 2 commented:

  > *I've had a few GPs that have said, you know, “I've been treating this person for 10 years and they've never had an interpreter. . . and now suddenly you're here. . . I thought I was doing OK, but actually I realised how much I was missing*”.

  However, questions were raised with regard to the extent to which the deaf community are aware of their rights to access an interpreter under the GP Access Scheme, which was extended to all deaf people, not just medical card holders during the COVID-19 pandemic.

- Several interpreters spoke to the importance of recognising the difference between sign language and spoken language interpreters, awareness of RISLI, and of the importance of recognising ISL interpretation as a very specific and nuanced skill set. Interpreter 1, for instance, pointed out that there is a need to challenge the assumption that *‘any interpreter will do’*. Further to this, Interpreter 1 also expressed concern around the appropriateness of using agencies focused on spoken language interpretation for deaf clients:

  > *We want people to look at the deaf community as a linguistic minority, but when the HSE do that, then they lock them in with spoken language interpreting agencies . . . I think some of the hospitals are starting to realise that, OK, we can't use the spoken language agencies because they're not checking the register* [RISLI]’.

- Two interpreters spoke to practical ways by which access to health care could be improved. Interpreter 3, for instance, made reference to the heavy reliance on text-based literature when providing information on medical conditions, and suggested that use of visual resources would be far more accessible to deaf people. Interpreter 5 called for native signers to be used to disseminate medical

information on social media and spoke to the relative ease with which video content can now be distributed, pointing out that: ‘*there is expertise in the deaf community here in making video content . . . so we literally have deaf interpreters that are trained*’ (Interpreter 5).

5. REPORT CONCLUSION & KEY RECOMMENDATIONS

Throughout the ISL HEALTH research project, it has become evident that there have been some positive developments in the arena of access provision for deaf ISL users in public healthcare settings over the past decade. These have resulted both from campaigns led by the deaf community and their representative organisations as well as from policy innovations within the HSE. A source of particular encouragement is the commitment to service improvement among a number of the access officers who participated in this research, not merely as a measure of compliance with policy or legislation, but as a means to widen access to public health services for universally improved health outcomes.

Notwithstanding this, persistent inconsistencies across public healthcare settings remain. These are often related to gaps in understanding on the parts of service providers which result in ad hoc, reactive and variable access provision. International evidence signposts what is required to address systemic discrimination as follows: education and training; ensuring consistent provision of qualified, accredited interpreters in healthcare settings; and collaborative approaches to systems design which engage deaf community expertise. Here in the Republic of Ireland, immediate priorities must be:

- Full implementation of the ISL Act 2017
- Fulfilment by public bodies of their public sector duties
- Better representation of deaf professionals and collaborators in organisational planning
- Addressing the inadequate provision of accessible mental health services for deaf people

Recommendations

Over the course of the *ISL HEALTH* project, the following action-oriented measures have been identified as being important for promoting and upholding the rights of deaf ISL users in public healthcare settings. While the majority of these recommendations signpost positive actions that public healthcare providers need to adopt or continue, many of these recommendations require a collaborative approach at the heart of which is engagement with Deaf community experiences and expertise.

1. **Promoting awareness of the Irish Sign Language Act 2017**

   Increasing the understanding of the provisions of the Act among both

- public healthcare providers (with specific reference to the public sector duty) and
- members of the Deaf community, to ensure that individuals know the full extent of their rights as upheld in law.

2. **Improving deaf-friendly communication channels**

- Significantly increase the amount of video content available with ISL on HSE website and to promote understanding that captioning alone is insufficient for quality access provision. This should be carried out in line with the principle of e-quality (Blanck, 2016) and European Accessibility Act 2025 (Directive 2019/882).
- Create ISL versions of information sheets and consent processes for clinical procedures.
- Develop collaborative solutions between HSE and agencies representing Deaf community interests – both national and local - who have vast expertise in accessibility and the development of resources. Regular and sustained consultation with Deaf community representatives is vital for alignment with Article 33 of the UNCRPD and to ensure that conversations around access remain culturally informed.
- Improve email and SMS text facilities which are resourced and operated on an equivalent basis with telephone-based communication. This is vitally important for making appointments, but also to enable deaf people to participate fully in feedback mechanisms which inform ongoing service development.

3. Recognising and understanding the value and necessity of sign language interpretation

- Promote understanding and awareness of the importance of sign language interpretation at all stages of a service user's engagement with a public healthcare provider.
- Take time to ascertain the interpreting preferences of deaf service users in all situations, to maximise their agency and autonomy, with due regard for gender-based and/or cultural sensitivities.
- Recognise that interpretation is necessary for and benefits both healthcare providers and deaf service users who use ISL. Clinicians who are not proficient in ISL cannot engage effectively with ISL users without the presence of a deaf person's preferred registered interpreter. Trying to do so is very likely to negatively impact on effective diagnosis and inhibits meaningful, fully informed interactions with patients.
- Streamline the process of interpreter provision through development of standardised procedures across all CHOs around booking, sanctioning and payment of interpreters. Emergency situations are especially challenging and there is an acute need for a robust protocol for effective crisis responses which uphold the rights and preferences of deaf ISL users.
- Provide appropriate continuing professional development, professional mentorship and debriefing opportunities for deaf and hearing interpreters; this is important to ensure readiness for working in acute healthcare settings and to maximise the retention of interpreters who are properly supported to work in such challenging environments.

4. Providing appropriate and adequate resources for Access Officers to support them to fulfil their role

- Designate and protect budgets with a commitment to ensuring access provision.
- Create regular, sustained opportunities for Deaf Awareness Training of all public-facing staff in public healthcare settings.
    - Deaf Awareness Training should be a standalone offering, rather than being incorporated into broader disability training, which is usually delivered by hearing personnel and lacks the nuance and lived experience element of training which is provided by native ISL users.

  - Deaf Awareness Training should reflect the fact that deaf people's communication needs vary widely, and training should be tailored to specific requirements of service users in response to particular settings.
- Develop standardised, consistent procedures across and within hospitals to ensure that patients' communicative rights are upheld universally, without discrimination, irrespective of location.
- Provide and maintain technology which is fit for purpose to facilitate remote sign language interpretation.

5. Recognising and replicating existing good practice

- Address the policy-implementation gap which is detected in relation to the HSE's policies *On Speaking Terms* (2009) and *National Guidelines on Accessible Health and Social Care Services* (HSE/NDA, 2016). This can be enhanced and complemented through the promotion of increased awareness of public sector duty as set out in the ISL Act 2017.
- Create opportunities for collaborative conversations in which a spotlight can be given to local or ad hoc positive access interventions, with a view to replicating those in a consistent way across all CHOs.

6. Committing to accountability

Develop assessment and feedback mechanisms whereby public healthcare providers are:

a) aware of their public sector duty and provided with sufficient support and resources to meaningfully fulfil their obligations.

b) able to recognise systems of audist privilege.

c) supported to co-operate with monitoring and feed-forward processes; this should include the development of practices, processes and policies; a commitment to their implementation through regular audits of communication practices by client-facing services; and co-operation with ongoing review mechanisms.

d) expected to engage fully and meaningfully with Deaf service users and organisations representing the interests of deaf communities.

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Kerry Deaf Resource Centre

PROVIDING ACCESS FOR DEAF IRISH SIGN LANGUAGE USERS
GUIDANCE FOR PUBLIC BODIES

The Irish Sign Language Act 2017 recognises ISL as an official language of the State. The State recognises the right of Irish Sign Language users to use ISL as their native language and the corresponding duty on all public bodies to provide ISL users with free interpretation when availing of or seeking to access statutory entitlements and services.

This guide is intended to support public bodies in fulfilling their obligations in accordance with the Irish Sign Language Act 2017 (Section 6) and the Irish Human Rights and Equality Commission Act 2014 (Section 42). To achieve positive and meaningful engagement with ISL users, public bodies, including courts, should:

Ensure funding and clear policies are in place for the booking, sanctioning and payment of sign language interpreting access [to include in-person interpretation and remote web-based video services].

- Engage the services of trained and accredited sign language interpreters. For more information: **https://risli.ie**
- Ensure that the provision of interpretation shall be at no cost to the person involved
- Understand the importance and purpose of sign language interpretation, recognising its value to all parties in public body communication, both hearing and deaf
- Make policies around interpretation easy to access. Such policies should:
  - Be applied consistently throughout the organisation to avoid ad hoc patterns of access provision
  - Feature in the induction of new public sector employees & upskilling of current employees
  - Be regularly reviewed and updated to keep in line with best practice
  - Have built-in compliance monitoring and a clear procedure for handling complaints

Create and maintain accessible communication systems to ensure that ISL users can communicate independently and autonomously with public bodies.

- Maintain adequately resourced text messaging, video-calling and email systems, which are monitored on a par with telephone-based communication, and which have a reliable and timely reply facility
- Feature ISL and subtitled information across communication channels, including websites and social media
- Design communication systems which allow appropriate time frames for ISL-English interpretation to be provided to an acceptable standard

Foster positive, inclusive attitudes and demonstrate commitment to providing equitable, non-discriminatory access to ISL users.

- Engage on an individual basis with each ISL user to establish their communication preferences, ideally from the first interaction
- Recognise and understand public bodies' obligations under law to promote equality of opportunity and to protect the human rights of persons to whom they provide services, including ISL users
- Explore opportunities for staff in public bodies to undertake Deaf Awareness Training and to acquire ISL skills, in line with broader diversity awareness

The content of this guide is informed by input from members of the deaf community in Ireland, based on their experiences of public bodies. **https://www.ucc.ie/en/iss21/researchprojects/researchprojects/islaccesspublicbodies**