Approved communication support for deaf patients in Ireland during COVID-1992

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International Sign video of this chapter



https://vimeo.com/542012467/dd3588d53b

Ireland's social services are often considered similar to those of the United Kingdom due to the shared history. Yet, in reality, they are starkly different, as Ireland's were developed and shaped with the Catholic Church in a leading role. This complicated history has resulted in a two-tier health service: public and private. The Health Service Executive (HSE) is responsible for the former, including the provision of public health information. Therefore, the Irish Deaf Society's interactions have mostly been with the HSE during the pandemic.

At the beginning of the pandemic, the HSE responded to the consultation with deaf community stakeholders on access to coronavirus information and immediately improved the level of public health messages accessible to all. The HSE has been consistent in engaging interpreters for their daily briefings during the pandemic. However, there have been challenging issues, including the different government bodies (other than the HSE) not recognising the impact on linguistic minorities when a majority of their communications are only available in English. Also, the dissemination of misleading information about the pandemic on social media created uncertainty and mistrust. By way of illustration, some members of the deaf community (like many hearing people) asserted publicly that lockdown

⁹² This article is mainly based on a webinar presentation made by Elaine Grehan on 21 October 2020 as part of the EUD Covid-19 Webinar Series entitled 'Accessibility in Hospitals', but with some additional context and updated information. Also see https://www.eud.eu/news/webinar/past-webinars/covid-19-series-accessibility-hospitals/

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⁹⁶ Founded in 1981, the Irish Deaf Society is Ireland's national representative organisation for deaf people as a community, and its main offices are located at Deaf Village Ireland, in Cabra, Dublin.

and restrictions were unnecessary and part of a conspiracy against liberty. Such information left a sizable number of vulnerable deaf people doubtful about the restrictions, and the Irish Deaf Society (IDS) has taken steps, including making direct representations to local members of parliament and various government bodies, to ensure that communications from the government are presented accurately to the deaf community and are clearly understood. This chapter begins by briefly outlining the legislative background that affects deaf people's access to public health information and services in Ireland, before describing the engagement that took place between the IDS, HSE and other stakeholders during the pandemic.

The Irish Sign Language Act⁹⁷ was enacted on 24 December 2017, and many of the articles were in the process of being implemented during the coronavirus crisis. The Act obliges public bodies to employ competent practitioners for interpreting assignments, and this necessitated the setting up of a national register of interpreters, which was launched by the Sign Language Interpreting Service (SLIS)98 a little over three years later, in January 2021⁹⁹. Several other pieces of legislation support the Irish Sign Language Act and place pressure on public bodies to use an equitable approach when providing services and information. Article 24 of the Irish Human Rights and Equality Commission Act 2014 creates a 'public sector duty' requiring authorities to ensure their policies and services are equitable and fair to all citizens, 100 and the Equality Status Act (2000-2018) outlaws discrimination on nine grounds, including disability. The Irish government has also ratified the UNCRPD. Ireland therefore has a legislative basis for public bodies to facilitate access for deaf and hard of hearing citizens, but the lived experiences and dissatisfaction of those in receipt of services suggest that there is still much work to do.

In March 2020, COVID-19 arrived, and Ireland's health services scrambled to adapt and provide testing and contact tracing services. Many initiatives were hastily developed without time for consultation and stress testing. At the start of the pandemic, the IDS consulted with deaf community organisations to create an online document detailing accessibility gaps in the government's response to the crisis. Many stakeholders provided input including the board and senior staff of the IDS; organisations running deaf residential services (e.g. the Catholic Institute for Deaf People); and interpreter organisations and service providers (e.g. the Council of Irish Sign Language Interpreters, the SLIS, the agency Bridge Interpreting,

⁹⁷ The text of the Irish Sign Language Act is available at http://www.irishstatutebook.ie/eli/2017/act/40/enacted/en/html

⁹⁸ The SLIS (Sign Language Interpreting Service) was established in 2007 with state aid through the Citizens Information Board and the Department of Social Protection.

⁹⁹ The Register of ISL Interpreters is available at https://risli.ie/

¹⁰⁰ An explanation of Article 24 in ISL is available at https://vimeo.com/467731986

and Chime¹⁰¹ which is an NGO that is largely funded by the HSE). The IDS collated the feedback into the online document and, in partnership with Chime, engaged with HSE staff to discuss several accessibility gaps. Firstly, no information was being made available in ISL initially, so deaf people did not have access to COVID-19 public health guidance and were vulnerable to the spread of misinformation. Secondly it was difficult for them to contact their GPs, as the public were advised not to go to GP surgeries but to phone them, and there was no provision made to text or email, as deaf people were used to doing before the pandemic. Also, only those with a medical card¹⁰² or GP card were entitled to have an ISL interpreter for a consultation, making it prohibitively expensive for some deaf people to see their GP. Within the COVID-19 testing process, there were communication barriers for deaf people due to ISL interpreters not being provided and healthcare staff wearing face masks, making lipreading impossible. Finally, positive cases were contacted by phone call only, meaning that a deaf person could not receive their result. To mitigate some of these problems, the IDS made representations to the HSE and the Minister for Health which resulted in the creation of a document that deaf people could take with them to healthcare appointments (see Figure 1).

In April 2020, the HSE, IDS and Chime agreed to set up a small project team involving their representatives and began addressing these accessibility gaps. The type of engagement is vital to note. From the beginning, the HSE staff were committed to weekly meetings to discuss the challenges, take the deaf community's feedback to the relevant units in the Department of Health, and report on the progress. The conversation went back and forth as the challenges were discussed over many weeks and the collaborators made compromises and shared ideas. This process was more successful when the IDS brought creativity and solutions to the meeting, not only problems. For example, they advised on how to make ISL translations of websites and essential information leaflets on the pandemic. The HSE staff provided a single point of contact and helped guide and co-ordinate the IDS's feedback and the government's responses. This would likely have been impossible if the IDS had to engage in discussions separately with all of the parties involved, e.g. the Minister of Health, Department of Health, private health providers and private health insurers.

During the discussions, it became clear that many healthcare workers had little to no experience engaging with deaf people and did not know what commitments the Department of Health had already made in terms of accessibility. For example, many healthcare staff did not know that there

¹⁰¹ Prior to its rebranding in 2018, Chime (https://www.chime.ie) was known as DeafHear.

¹⁰² This card entitles a patient to access healthcare services free of charge, but it is restricted to those who earn less than a certain threshold (see https://www2.hse.ie/services/medical-cards/medical-card-application-process/how-much-you-can-earn-and-still-qualify-for-a-medical-card.html).

was a duty to organise an interpreter; some were not allowing deaf people to use their smartphones for remote interpreting; and some refused to lower their face masks or find a suitably distanced location to facilitate visual communication. The IDS therefore decided that it would be beneficial to produce a concise document listing the guidelines, that a deaf person could bring with them to a healthcare setting either as a paper printout or on their phone. The document was uploaded to the IDS's website and the HSE posted it on their own website, newsletters, and communications to all healthcare staff. A link to it was also sent out to stakeholders including GPs and NGOs throughout the country.¹⁰³

Healthcare staff have access to guides on communicating with deaf people and working with interpreters on the HSE Partner Resources web page.

Healthcare staff will book a sign language interpreter, which may be face-to-face or remote interpreting.*

A patient can bring their smart device to facilitate remote interpreting using WiFi.

If an onsite interpreter is required (for example, tactile interpreting for Deafblind) healthcare staff will provide PPE.

Face masks should be removed at a social distance to facilitate lip-reading if required. Healthcare staff do not need to wear a facemask if physical distance can be maintained.**

Lip reading comprehension can be lower than 30%; please support communication by writing information.

Figure 1: The document intended for use by HSE staff and deaf patients whose first language is ISL, detailing approved communication support that should typically be provided in healthcare settings

The HSE, to date, have been mostly cooperative with the IDS despite some hiccups and tensions along the way, such as difficulties in identifying the appropriate contact persons and procuring interpreters, and the need to dispel inaccurate assumptions about certain linguistic and cultural issues (for example, the erroneous assumption that deaf people are a homogenous group). This work during the pandemic has resulted in several engaging lessons that the IDS can draw on to develop future relationships with public bodies. For example, by engaging with the HSE about deaf awareness on a regular basis, it was possible to ascertain what knowledge they needed, which is likely to be similar for other public bodies. Having addressed the barriers in this dialogue and created a partnership in which the HSE agreed to provide interpreters and find ways to make services more accessible for deaf people, the IDS is now better equipped to do the same in other policy areas in the future.

¹⁰³ See https://www.hsc.ie/eng/services/news/newsfeatures/covid19-updates/partner-resources/covid-19-irish-sign-language-isl-resources/

Such cooperation was virtually non-existent a decade ago and became a reality within a brief timeframe. This is a tribute to all concerned in the many levels of cooperation. The HSE's Communications Department were highly involved and helpful. There was an immense amount of goodwill on all sides, which charities might feel is not always the case. This process has enabled the IDS to strengthen its advocacy for a more rights-based approach to accessibility and consideration of Universal Design principles at the very beginning of service planning. Delivering on the commitments of the ISL Act and the UNCRPD should result in deaf people being empowered to lead full and independent lives of their choosing with equal access to the range of services that other citizens enjoy.