

## Chime Submission

re the consultation on the

### Draft Initial State Report under the Convention on the Rights of Persons with Disabilities

#### 1.0 Introduction

1.1 Chime is the National Charity for Deafness and Hearing Loss. Chime was founded in 1964 and is dedicated to a society where deafness or hearing loss does not limit individual potential, personal choice or quality of life. Chime works to achieve this through advocating for a more accessible and inclusive society and providing a range of personal support services for Deaf and Hard of Hearing people. Chime's services entail a holistic approach, addressing the person's social, technological and emotional needs.

1.2 Chime welcomes the publication of the draft Initial State Report under the Convention on the Rights of Persons with Disabilities. We welcome the opportunity to comment on the draft Initial Report, and are comments at this point in time are focussed on the issues that are of most significance to the lives of Deaf and Hard of Hearing people. The comments draw on organisational knowledge and on issues identified in a number of focus groups with stakeholders.

1.3 A significant portion of the population is affected by deafness or hearing loss. Approximately 200 children are diagnosed each year with hearing loss, with the majority diagnosed within a few months of birth. The Deaf community has approximately 5,000 members whose primary language is Irish Sign Language (ISL). Those who have acquired a hearing loss in adulthood are a much larger group. The HSE estimates that 8% of all adults (approximately 300,000 people) have a moderate or greater hearing loss and require audiological support. The prevalence of hearing loss increases greatly in later life, so that by the age of 70 approximately 50% of the population have acquired a significant hearing loss.

1.5 Hearing impacts on communication, and communication is fundamental to many aspects of life for both children and adults. The communication challenges faced by Deaf and Hard of Hearing people – young and old, at home and in the community, at work or at play – are a constant presence that cut across many domains of daily life. As a result, the substance of many Articles in the CRPD is relevant to the lived experience of people who live with deafness or hearing loss. This submission can not deal comprehensively with all of the issues, but focusses on those Articles which are of most significance at this point in time.

## **2.0 General comments on the draft Initial State Report**

2.1 Chime acknowledges that the drafting of the Initial State Report under CRPD is a momentous and onerous task. However, while the draft Report is quite comprehensive in listing the legislation, schemes, services and arrangements that are currently in place to support people with disabilities (PWDs), it is weak and inconsistent in reporting on the impact and adequacy of these measures. This submission highlights the current lived experience of Deaf and Hard of Hearing people in Ireland, which is considerably short of what would be the case if all the measures listed in the draft Report were fully implemented and fit for purpose.

2.2 Section 18 of the draft Report references the number of people who indicated that they had a disability in Census 2016. It is important to note that the number of people reported in Census 2016 as having hearing loss and those who communicated through ISL are considerable underestimates, primarily in our view as a result of the poor construction of the relevant questions in the Census questionnaire. In any event, as an illustrative example, Census 2016 reported 103,676 people as experiencing 'deafness or a serious hearing impairment'. However, based on hearing loss prevalence studies, the HSE concluded that 8% of adults in Ireland (300,000 people) have a moderate or greater hearing loss and are in need of audiological support. A moderate hearing loss equates to the World Health Organisation's definition of a 'disabling hearing loss'.

## **3.0 Specific Rights**

3.1 Re Article 5 – Equality and non-discrimination, and Article 9 – Accessibility, the draft Report refers to the Public Sector Equality and Human Rights Duty (Section 27), the obligations of public sector organisations in the provision of accessible services (Section 33) and the statutory obligations re accessibility required under the Disability Act (Section 75). The reality is that for many Deaf people, these duties and obligations are not fulfilled. In 2017 a CIB report on 'Information provision and access to public and social services for the Deaf Community' found that the experience of Deaf citizens in this regard was 'overwhelmingly negative'. While some progress has been made in the interim and the Irish Sign Language Act has been enacted, many provisions of the ISL Act remain unimplemented and many Deaf citizens, especially those who are most vulnerable, continue to have difficulty accessing public services.

3.2 Re Article 7 – Children with disabilities and Article 25 – Health, the draft Report refers to Progressing Disability Services for Children and Young People and states that this model provides a clear referral pathway for all children through an integrated care model (Sections 48, 242 & 352). This is certainly not the case for Deaf and Hard of Hearing children with complex needs. The HSE have acknowledged the need for a specialist multi-disciplinary service for Deaf and Hard of Hearing children with complex needs within the PDS framework (in their Advisory Group Report of 2017). This report acknowledges that many of these children have a 'non-specific diagnosis of co-occurring disorder', as the assessing clinicians lack the necessary specialist skills and competencies to assess these children properly, that this results in 'difficulties in accessing appropriate educational placement' and that 'the child's learning potential is therefore misunderstood'. Although such inadequacies in service provision for these children inevitably results in negative lifelong consequences, to date no steps have been taken to put the recommended multi-disciplinary specialist team in place. In fact recently the HSE acted to remove from a Deaf school the one available specialist clinician in the country (a Speech and Language Therapist) – an issue that has been raised in the media and the Oireachtas.

3.3 Re Article 7 – Children with Disabilities, and Article 24 – Education, the Access and Inclusion model is generally working well and is a model of good practice (Sections 50, 302, 303). One issue causing frustration for families of Deaf and Hard of Hearing children is that their young child has access to assistive technology in the early childhood setting that supports their child’s communication and language acquisition – but this equipment is not available to them for use in the home and community setting.

3.4 Re Article 11 – Situations of risk and humanitarian emergencies, the expanded Summer Programme was welcomed by families (Section 130), and the engagement of the HSE and deaf organisations to develop Covid-19 information and guidelines for health professionals working with Deaf and Hard of Hearing and for the Deaf community itself was also welcome (Section 133).

3.5 Re Article 13 – Access to Justice, the active participation of Deaf citizens in the justice system on a par with hearing peers is a significant step forward and constitutes important progress (Section 163).

3.6 Re Article 14 – Liberty and security of the person, the experience of Deaf prisoners to date has not been one where they have had equal access to healthcare (Section 180) or other prison services, such as educational services. Chime is aware of many instances involving Deaf prisoners where medical consultations and access to educational services in prison settings have not been facilitated with ISL interpreters.

3.7 Re Article 19 – Living independently and being included in the community, and Article 25 – Health (Sections 228 & 337), the HSE and the State have continually failed to meet the needs of Deaf people who need support to live independently in the community. A significant number of Deaf people who communicate in ISL and who cannot live independently without in-home support have been placed in community settings with other hearing residents and hearing staff who cannot communicate with them. In a number of other cases Deaf persons have been placed in a Deaf specific community service outside the State. These people have not been able to exercise choice and control over where and with whom they live – contrary to Article 19 and stated Government policy within Time to Move on from Congregated Settings. In fact the current placements of these people is resulting in a deterioration rather than an improvement in their quality of life and their social, emotional and language functioning. In one case recently, a Deaf lady took an action in the High Court which resulted in her being offered a placement in a new Deaf specific service with care support provided in ISL. However, others continue to live in settings where fundamental Human Rights are being denied to them.

3.8 Re Article 20 – Personal Mobility and assistive technology for independent living, and Article 26 – Habilitation and rehabilitation (Sections 255 , 256 & 363), Deaf and Hard of Hearing people have very limited access to AT. There are high levels of unmet need throughout most of the country, as the adaptive AT required is much more expensive than mainstream equipment (e.g. flashing doorbells, alerting devices such as baby alarms and smoke alarms, etc). Also, supports and measures to access AT such as this varies greatly from one CHO area to another.

3.9 Re Article 21 – Freedom of expression and opinion, and access to information, there has been some positive progress in recent times, particularly in relation to access to public health information through ISL. It is most welcome that Covid-19 updates from Government and the HSE are now broadcast with ISL interpretation on screen. However, the Broadcasting Authority of Ireland is still in contravention of its public service obligations in relation to the operation of the Sound and Vision scheme. This is a public scheme where audio-visual projects that are funded through public monies generated from the TV licence fee should be required to be fully accessible and include ISL presentation (Section 259 & 262). Despite

many years of lobbying the BAI, they have continued to fail to implement this scheme in accordance with policy and legislation.

3.10 Re Article 24 – Education. Although persons with disabilities have equal rights of access to education, this right is not being fulfilled for a number of Deaf children whose first language is ISL (Section 286, 288, 293, 294). Many of their teachers do not have the required fluency in ISL to give equal access to the curriculum – even in Deaf schools and units for Deaf children. In response the Department of Education seek to employ in-class ISL supports via the SNA scheme, which does not attract candidates with the required skills and fluency. Despite provisions in the ISL Act re minimum qualifications for teachers of Deaf children, and the establishment of a scheme to provide ISL for Deaf children in recognised schools, these measures have not yet been implemented. As a result, Deaf children whose first language is ISL do not currently have equal access to education, which is reflected in the low level of representation of Deaf students in Third Level education, notwithstanding some increases in recent years (Section 300).

3.11 Re Article 24 – Education, the Department of Education in Ireland (unlike the UK) do not publish details of the outcomes for Deaf and Hard of Hearing children in State Examinations. The failure to publish these outcomes means that there is no evidence to show whether or not these children are achieving educational outcomes on a par with their hearing peers as envisaged by the National Council for Special Education, or if they are being provided with equal access to education (Sections 286, 294).

3.12 Re Article 24 – Education, the recent changes to resource allocation for pupils with SEN has resulted in Deaf and Hard of Hearing receiving lower levels of support (Sections 310, 311). Parents have reported to Chime that in their experience school managers often do not fully understand the learning needs of Deaf and Hard of Hearing children and have prioritised children with challenging behaviour for increased resource allocation. In one instance a school indicated that their pupils who had bilateral cochlear implants no longer had a disability or SEN. This is clearly not in accordance with international research, but is indicative of a lack of training, competency and understanding of the area of deaf education.

3.13 Re Article 25 – Health and Article 26 – Habilitation and rehabilitation, Ireland has a very low level of uptake of hearing aids and does not have a universal health approach to hearing loss as recommended by the WHO. Ireland prescribes hearing aids at less than half the rate of the UK. Those with medical cards are entitled to free audiology services from the HSE – but many must wait more than 3 years for an appointment. The national HSE audiology waiting list is now over 20,000 and is five times greater than it was seven years ago in 2014. People without a medical card must purchase hearing aids themselves, and while some may avail of a state grant of a maximum of €1,000, this typically covers just 30% of the cost, meaning individuals must pay an average of €2,330 each. Those with hearing loss who have a medical card, despite the long waiting lists, are twice as likely to have hearing aids as those who don't have a medical card. The State's approach to hearing care/ hearing loss is clearly not consistent with an equitable approach to healthcare (Section 348, 356), and is in contravention of Articles 25 and 26.

3.14 Re Article 27 – Work and employment, Deaf and Hard of Hearing people are more likely to be unemployed compared to the wider workforce. They are also more likely to experience under-employment as they are often not considered for promotion or senior positions, and they lack in-work supports. This results in higher rates of poverty amongst people who are Deaf or Hard of Hearing. There are some reasonable accommodations and supports (Section 397), but these are completely inadequate. For example, a Deaf person is entitled to get an ISL interpreter for a job interview, but if they get the job, they are not entitled to any on-the-job ISL supports. Similarly, captioning is not available as a workplace support for Deaf or Hard of Hearing employees, which means communication in the workplace is a major barrier for

many. Employment supports in the UK are illustrative of how Deaf and Hard of Hearing people can both access and progress in the workplace with the right supports.

3.15 Re Article 29 – Participation in political and public life. Generally Deaf and Hard of Hearing people have no difficulty in exercising their right to vote, but a Deaf person is hugely disadvantaged in putting themselves forward for election. In 2020 a Deaf person was nominated for the Seanad elections. He was greatly disadvantaged in trying to reach out to voters, as he had to fund ISL interpreters himself in order to do canvas voters. Implementation of Section 9 of the ISL Act could go some way to addressing this inequality, if provided for in the relevant guidelines.

3.16 Article 30 – Participation in cultural life, recreation, leisure and sport. Deaf and Hard of Hearing people face major barriers in participating in community life (Section 419). The ISL Act (Section 9) allows for the Minister for Employment Affairs and Social Protection to provide funds to facilitate Deaf people to access social, educational and cultural activities, but unfortunately this is not yet in place. Implementing this provision would be a very positive development in supporting active citizenship and participation for the Deaf community. Enforcement of reasonable access accommodations such as captioning, assistive listening devices and ISL interpretation in venues that are in receipt of public monies, such as theatres and other public performance venues, should be introduced.

#### **4.0 Summary**

4.1 Chime welcomes the publication of the draft Initial State Report under the Convention on the Rights of Persons with Disabilities. We welcome and recognise the good intentions of Government with regard to the CRPD, but there are significant issues to be addressed, and determination and perseverance will be required.

4.2 In terms of the CRPD and the current situation in Ireland, there are many outstanding issues that are of concern to Deaf and Hard of Hearing people. The most egregious concerns include providing a home of choice to Deaf people who are inappropriately placed, providing a specialist service for children with complex needs, addressing educational inequalities and providing fair and reasonable ear and hearing care for all those experiencing deafness or hearing loss.

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