

Chime Submission

to the

Public consultation on Disability Social Care Services (2022-2025)

October 2021

Introduction

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.

Chime welcomes the opportunity to make a submission on the Disability Social Care Services consultation to guide planning for the next four years. People who are Deaf or Hard of Hearing continue to face many barriers in living lives of equal opportunity, choice and participation on a par with their hearing peers, despite some progress in recent years. This is especially so for those who may require some additional support to reach their potential and live a life of their choosing with equal opportunities to participate in community life. It is important to remember that deafness in itself does not limit the potential of those who live with it, rather it is the societal barriers they face in their daily lives that results in inequality and unrealised potential.

Given the short consultation period and the request for submissions to be brief and concise, this submission focusses on the most important issues limiting the lives of Deaf and Hard of Hearing people from a social care service perspective, and where appropriate, it refers to existing reports and research to validate existing unmet need. If desirable, Chime will be more than happy to provide further details on such information on request. We are guided by the consultation objective to provide details of what "you think the biggest gaps are and what you think should be the most important actions taken over the next four years."

Summary

1. Establish a multi-disciplinary specialist service for Deaf and Hard of Hearing children under the Progressing Disability Services framework.

Details of the need for this service, the number of children with complex needs who require the service, and the specialist personnel required to deliver the service are contained in the Report of the National Advisory Group on Specialist Reports for Deaf Children to the National PDS 0-18s Working Group completed in November 2017.

The ongoing failure to deliver this service means that PDS is failing Deaf children with complex needs in terms of its objective to deliver fair and equitable support to all children, and has lifelong negative consequences for many of the children concerned.

2. Provide a range of supported accommodation supports for vulnerable Deaf people with in-home care and support provided in ISL, with a complementary community based multi-disciplinary team and allied services.

Details of unmet need and inappropriate placements for Deaf people who communicate in Irish Sign Language (ISL) and need support to live in the community are contained in the HSE led Report from the Working Group on the Residential Needs of Vulnerable Deaf Adults completed in December 2015.

This report identified 165 vulnerable individuals in need of a range of accommodation and/or specialist community supports delivered in ISL. For the vast majority of them, nothing has changed in the interim, and none of the recommendations have been progressed by the HSE. The outcomes of the unmet need for some of these people has resulted in ongoing chaotic lifestyles, acute mental health difficulties and premature death.

1. Chime

- 1.1 Chime is a national charity incorporated in 1964 as the National Association for the Deaf. It supports and represents members of the Deaf community, Deaf and Hard of Hearing children, adults with acquired hearing loss, and people with tinnitus.
- 1.2 There is an estimated 5,000 Deaf people in Ireland whose first language is ISL. Many face significant barriers across a range of domains – early development, education, employment and social participation, in their daily lives. While the Irish Sign Language Act is helping to reduce some of these barriers through increased access to some services, many barriers still remain. Education is one case in point where equal access is far from being realised for some children. Those with additional needs, approximately 40% of the Deaf population, are most vulnerable and least likely to benefit from progress currently underway.
- 1.3 Approximately 1-2 children per thousand are born with hearing loss and the prevalence doubles over the lifespan of childhood. Currently there are over just 5,000 children in the education system at present. Research commissioned by Chime and currently in press indicates that these children are at four times the risk of emotional difficulties compared to hearing peers. Deaf and Hard of Hearing children are much less likely to progress to Third Level Education compared to hearing peers, and approximately 40% will have an additional need.
- 1.4 People with age related acquired hearing loss comprise 8% of the adult population – 300,000 people. Ireland has a very low rate of uptake of hearing aids, where cost and other factors such as stigma are a factor. Only one in five older people with hearing loss had hearing aids, while those with a medical card are twice as likely to have hearing aids (TILDA, 2017). Unaddressed hearing loss has been linked to decreased quality of life and increased health risks such as depression and cognitive decline (Saito, Lancet Commission).
- 1.5 Approximately 10% of the population experience tinnitus on an ongoing basis, with 10% of these people (1% of the population of approximately 50,000 people) experiencing tinnitus as a troublesome and lifechanging condition. Chime provides support and advice to people troubled by tinnitus.

2. Consultation

- 2.1 Chime consults regularly with its stakeholders. It has a Board of Directors with members representing different client groups. It has a National Stakeholder Forum that meets bi-annually with membership comprising Deaf and Hard of Hearing people and other organisations active in the sector. It has recently completed a new strategic plan that involved intensive consultation with stakeholders, including personal interviews and focus groups. Feedback from these consultations has directly informed the content in this submission.

3. Deaf and Hard of Hearing children

- 3.1 There are approximately 5,000 Deaf and Hard of Hearing children in Ireland. Most attend mainstream schools, but some attend special schools or units for Deaf children.
- 3.2 Since 2013 the newborn hearing screening programme has meant that congenital hearing loss is diagnosed much earlier, and so parents and guardians are aware from a much earlier stage than previously. This means that earlier intervention is possible and better outcomes are achievable for the child's future.

- 3.3 While some early interventions now take place, e.g. the fitting of hearing aids or cochlear implants, others are still lacking, e.g. access to speech and language therapy and access to ISL tuition. Overall there is a complete lack of a coordinated early intervention programme to support children and families in accordance with identified best practice. This undoubtedly contributes to poor outcomes for many children.
- 3.4 Approximately 40% of Deaf and Hard of Hearing children have an additional need. Some have complex needs that are beyond the competency of primary care or disability services clinicians. These children can experience delays in diagnosis, receive 'non-specific' diagnoses, or receive a misdiagnosis, all of which can result in serious negative lifelong consequences. This is recognised and detailed in the Report of the National Advisory Group on Specialist Reports for Deaf Children to the National PDS 0-18s Working Group completed in November 2017.
- 3.5 This is a serious gap in equitable service provision for Deaf and Hard of Hearing children that must be prioritised immediately.
- 3.6 Children's development is reliant on a number of core elements working together to support the child: family, healthcare and education are key examples. Some Deaf and hard of Hearing children, particularly those whose first language is ISL, are being failed across a number of domains. ISL Home Tuition and inschool access to the curriculum in ISL are key problem areas that are the responsibility of the Department of Education. It is imperative that there is appropriate supports in place across all agencies and Departments if the efforts of one Department or agency are not to be undermined by the omission of another, and more importantly, if the development of individual children is not to be unjustly compromised.

4. Vulnerable Deaf adults

- 4.1 The ISL Act has begun to reduce some of the access barriers in daily living experienced by Deaf people, although many barriers still remain. While this is welcome, it is important to note that to date the benefits arising from the ISL Act have been primarily experienced by Deaf people who are independent and self-sufficient, are able to self-advocate, and can proactively pursue improvements in access and service provision. In effect, this means that some members of the Deaf community are being left further behind.
- 4.2 Up to 40% of Deaf adults may have an additional need, and this combined with the additional challenges of living in a hearing world with many barriers results in a high rate of vulnerability amongst the Deaf population. So far, the impact of the ISL Act has made little difference to many of these people.
- 4.3 One area of acute vulnerability and need are those Deaf people who cannot live independently and are in need of some level of inhome support to live in the community. A review of needs and inappropriate placements for Deaf people who communicate in Irish Sign Language (ISL) and need support to live in the community are identified in the HSE led Report from the Working Group on the Residential Needs of Vulnerable Deaf Adults completed in December 2015. This report identified 165 vulnerable individuals in need of a range of accommodation and/or specialist community supports delivered in ISL. For the vast majority of them, nothing has changed in the interim, and none of the recommendations have been progressed by the HSE. The outcomes of the unmet need for some of these people has resulted in ongoing chaotic lifestyles, acute mental health difficulties and premature death.
- 4.4 Approximately one third of the 165 people were already in a residential placement. Approximately 30 were resident in the only designated Deaf residential service in the state – a congregated setting which is currently in the process of closing down. While this service was based on an out-moded institutional model, it had the advantage of providing support and care through ISL. A further 30

vulnerable Deaf people were in a variety of residential settings where they have no access to communication – in contravention of basic UNCRPD and human rights principles. This continues to be the case.

- 4.5 The Report made a series of recommendations for a range of community based services and accommodation supports to be delivered through ISL to meet the needs of the individuals identified. Since the Report was completed, there has been very little progress. A small number of Deaf people have recently benefitted from the planned closure of the Deaf congregated setting service, and a further three Deaf people are currently living in a new community home with support in ISL following a legal action by one of the tenants. There has been no proactive engagement to progress the recommendations of the 2015 Report, with the result that several dozen Deaf people continue to live in inappropriate placements, while others continue to live very dysfunctional lives and lapse into further levels of vulnerability.
- 4.6 As a testament to the lack of appropriate supports and services, six Deaf citizens are currently resident in a Deaf specific service in Northern Ireland, while a small number have also been placed on occasion in Deaf specialist services in the UK. Furthermore, the security of the placements of the six citizens in Northern Ireland are currently uncertain, as the current Deaf service provider organisation has indicated that it will be divesting itself from providing residential services.
- 4.7 There is an urgent need for investment in specialist community and accommodation service supports for vulnerable Deaf people. Currently many vulnerable Deaf citizens are being failed in a very fundamental way by the state due not to a lack of resources, (many resources are being deployed – but they are not fit for purpose, i.e. delivered through ISL), but through a lack of planning and leadership. The Report from the Working Group on the Residential Needs of Vulnerable Deaf Adults provides clear recommendations on what actions are needed.
- 4.8 On a positive note, the HSE in CHO9 have recently commissioned a new Day Service for a number of vulnerable Deaf people to be based on a Deaf accessible campus in Cabra, Dublin 7. This is a welcome initiative that recognises that delivering important policy initiatives such as Progressing Disability Services, decongregation and New Directions to vulnerable Deaf people requires a customised approach that recognises ISL as a core element in delivering effective care and support. Similar services are required in other areas of the country and should be progressed with urgency.

This submission provides a high level and brief overview of current critical social care needs of Deaf and Hard of Hearing people. Further information has been provided previously and elsewhere, and is available on request should it be required.

For further information on this submission, contact:

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