Oireachtas Special Committee on Covid-19 Response
Leinster House
Dublin 2

29th June 2020

Dear Committee Member,

Chime is delighted to provide a submission to the Special Committee on Covid-19 Response. We recognise the important work of the Committee and the many issues it has to consider.

Covid-19 has impacted greatly on all aspects of Irish society, and the disability sector is no different. Indeed in many respects the sector and people with disabilities have been impacted more severely than many others in society. While organisations face significant financial challenges, the most significant challenges are faced by people with disabilities and their families. Reopening our economy and returning to a sense of the 'new normal' will be difficult for everyone, but it will be even more difficult for people with disabilities.

It is vital that the full range of supports and services are in place as soon as possible, with enhanced and adapted service provision where necessary, to ensure that people with disabilities do not lose out more than others due to the impact of the pandemic.

Our submission highlights the impact of Covid-19 on Deaf and Hard of Hearing people and the particular challenges that this has presented to Chime and its service users. In drafting this submission we have consulted with other organisations in our sector, including Our New Ears, an affiliated parent led organisation. The submission also highlights some positive developments that transpired from Covid-19. We look forward to working with Government departments and State agencies to address these challenges in the best interests of our service users.

We will be happy to provide any further information or assistance required by the Committee.

Yours sincerely,

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Registered in Dublin No 21627 as National Association for the Deaf

Chime Submission

to the

Special Committee on Covid-19 Response

29th June 2020

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 opportunity to make a submission to the Special Committee on Covid-19 Response, particularly in relation to the impact on people who are Deaf or Hard of Hearing. In the course of drafting this submission, Chime consulted with a number of stakeholders in the sector, including Our New Ears, a parent-led organisation.

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 estimate that 8% of all adults (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 aged 70 approximately 50% of the population have acquired a significant hearing loss.

2.0 Covid-19 response for Deaf and Hard of Hearing people.

2.1 Access to public information.

2.1.1 Access to information from public briefings was an issue for the Deaf Community, particularly at the beginning of the crisis. After a series of representations by Deaf organisations, the HSE and latterly the Government began using ISL interpreters at public briefings. However there continued to be some occasions when this did not happen – for example, on Friday June 19th the Taoiseach made a statement from Government Buildings without any ISL interpreter present. Also, many live Government and HSE briefings were broadcast without subtitles, with the result that many Deaf and Hard of Hearing people could not access the information in real time – though they could access the information later in news bulletins and other media.

2.1.2 Access to information in ISL on Covid Testing and Covid Public Health Advice was also an issue for the Deaf Community initially. Over time, through engagement between Deaf organisations and the HSE's Service User/ Family Carer Representative Organisations Workstream, information was made available in ISL on the HSE website and other online media. This engagement with the HSE was very positive and productive in terms of improving access to information and resolving issues with the Covid-19 testing pathway. Accessing information and services remained extremely difficult for those who do not have access to the internet or social media.

2.2 **Covid testing: issues with access, pathways, and disaggregated data.**

2.2.1 The Covid-19 testing procedure was particularly difficult for many Deaf and Hard of Hearing people, the majority of whom rely on lipreading to assist with communication. The need for Covid-19 testing staff to wear face masks and other PPE made communication and the testing procedure much more stressful for Deaf and Hard of Hearing people.

2.2.2 Accessing a GP consultation during the restrictions was much more difficult for Deaf and Hard of Hearing people who are unable to make phone calls. Unless another family member was able to call on their behalf – many could not access a GP consultation. Typically many people with hearing loss call in person to their GP's surgery to make an appointment and then return at the appointment time. However, public advice was not to go to your GP surgery, but to make contact by phone. In reality, many Deaf and Hard of Hearing people had no option but to visit their GP's surgery to seek an appointment – but they often delayed doing so in attempting to follow public health advice.

2.2.3 Anecdotally, Chime believes that very few Deaf people were actually tested for Covid-19. There have been just a couple of instances where a sign language interpreter was engaged remotely to facilitate a Covid-19 consultation with a GP. There are no known instances to date where a sign language interpreter was engaged to complete contact tracing with a Deaf person. Given that there is an estimated 5,000 Deaf ISL users in Ireland and over 25,000 people have been diagnosed with Covid-19, one could expect that up to 25 Deaf people to have been diagnosed. The general view in the Deaf community is that the number of Deaf people diagnosed with Covid-19 is in the low single figures. Possible explanations for this are that less Deaf people were tested due to the additional barriers they experienced in making appointments; Deaf people were less likely to be infected with Covid-19 due to the social isolation issues many experience which reduced their risk of infection; and/or the provision of testing results and contact tracing may not have been completed with Deaf people who were diagnosed with Covid-19 (see 2.2.4). Chime believe that disaggregated data regarding the number of Deaf and Hard of Hearing who underwent a Covid-19 test would be very useful in shedding light on these issues.

2.2.4 The initial Covid-19 testing pathway contained a number of barriers that meant that a Deaf or Hard of Hearing person who did not make voice calls could not receive their test result if it was positive, and would also not complete a contact tracing procedure. The original Covid-19 pathway had a number of steps that relied on a person being able to make voice calls – something many Deaf and Hard of Hearing people cannot do. While a negative result was notified by text, a positive result was provided through a voice call only. To complete contact tracing, four attempted voice phone calls would be made to the person's contact number. If they did not answer any of these calls the contact tracing exercise would be terminated. The engagement with the HSE Service User Representation Work Stream was very useful in getting these issues addressed over time, which included a protocol at the point of referral to record if the person was Deaf or Hard of Hearing, if they could make voice calls, and if they required communication via ISL.

3.0 Impact of Covid-19 on daily life and services

3.1 Impact on education of Deaf and Hard of Hearing children

3.1.1 Most children with hearing loss attend mainstream classes, and are supported by a combination of a class teacher, a resource teacher, SNAs, communication support and the input and oversight of a Visiting Teacher of the Deaf. With school closures, for the most part all of these supports were lost to these children – meaning that school closures had a greater impact on their education and development compared to hearing peers.

3.1.2 Those children who attend Deaf schools or special units for deaf children in mainstream schools were also impacted much more severely by the school closures. Apart from the loss of specialist educational supports, many of these children communicate in ISL and are particularly reliant on their school environment to form peer relationships and friendships. These children were much more likely to experience feelings of isolation from friends and teachers when schools were closed. Given that Deaf and Hard of Hearing children are much more likely to experience emotional difficulties compared to their hearing peers, the additional stress experienced by these children is a matter of real concern.

3.1.3 Most Deaf and Hard of Hearing children rely on assistive technology and/or communication in ISL to support their development and learning. Many children did not have the same access to assistive technology or communication in ISL at home as they would normally have in school – with a consequent negative impact on their development and learning. Parents have noted the 'ludicrous' nature of the system where personal assistive technology to support communication for hundreds of children was 'locked in cupboards' in schools up and down the State – which should have been available for use by parents and children in the home to support communication and learning. Such assistive technology is available for use in the home for pre-school children under the AIMs protocols, but not for those attending primary or secondary school. This is a clear example of a failure to deliver a whole of Government approach with the child and family at the centre of service provision, combined with a failure to maximise benefit derived from public funds.

3.1.4 The Visiting Teacher of the Deaf is a vital service to parents and children. Nowadays the majority of children are diagnosed in the early months of life. Early intervention from a Visiting Teacher focusses on supporting parents to enhance the language development of their child, a critical time-sensitive developmental task of early childhood. For this cohort of children the risk of below average language development is well documented by international research. Consequently, it is very concerning that anecdotally parents report that a high number of families received much reduced contact from their Visiting Teacher during the Covid-19 restrictions. Several months is a very significant period in terms of a young child's language development. The failure of the DES and the NCSE to provide online platforms to provide advice and consultations to parents to support the learning and development of their child is regrettable and very concerning for parents. It contrasts sharply with the innovative provision of online ISL classes by parent volunteer organisations.

3.2 Impact of closure of audiology services

3.2.1 During Covid-19 restrictions, HSE Audiology services and private providers were closed for routine appointments, though in some instances emergency services were provided. Hearing aids require maintenance, occasional repairs and batteries to function. A significant number of people around the country, particularly older people who were cocooning, relied on Chime's online and outreach services to

provide minor hearing aid repairs and batteries to ensure they could continue to communicate with family and friends.

3.2.2 For children who use hearing aids, replacement of ear moulds and ongoing adjustment of hearing aid functionality is vital to ensure that the hearing aids are working optimally. Parents report that while some emergency HSE audiology services were provided to children, this varied from CHO to CHO on 'a service by service basis'. As this submission is being redrafted, there is no information available on when HSE audiology services will reopen, and we are informed that this process will be determined on an individual CHO basis. This process should involve a national approach that ensures consistency and equity of access to service provision.

3.2.3 Hearing aids (and other technologies such as Cochlear Implants and Bone Anchored Hearing Aids) provide a lifeline to communication and social interaction for those who use them. While it is somewhat understandable that certain services such as hearing testing and surgical procedures were cancelled during Covid restrictions – Chime and other stakeholders cannot understand how audiology services were not deemed an 'essential service' during this time. If restrictions need to be re-imposed in the future, we urge that audiology services are deemed essential to ensure children and adults can continue to communicate.

3.3 **Impact of cocooning on older people with hearing loss**

3.3.1 The impact of cocooning on older people with hearing loss is particularly severe. 50% of people aged over 70 have a significant hearing loss, and approximately one third live alone. Phone calls to family and friends was often the source of greatest comfort to older people during the restrictions – but many Deaf and hard of Hearing people cannot make voice calls. For the many of these people, a daily trip to the shop or the visit of the postman is their sole social interaction of the day. Cocooning ended trips to the shop – and so many experienced extreme levels of social isolation and loneliness during this time. Very few of these people had access to assistive technology which could have greatly reduced their levels of isolation.
(The HSE, ALONE and Chime are collaborating on a project to make a number of listening devices available to people who have severe levels of hearing loss, cannot use a phone for voice calls and are socially isolated. While still at an early stage, this project uses a standardised scale to measure the level of social isolation among participants. The scale ranges from 0 (highly socially connected) to 10 (highly socially isolated). The average level of the project participants to date is just over 7/10, compared to an average of 1.7/10 in the Irish Longitudinal Study of Ageing).

3.3.2 Accessing services, such as GP appointments, chemists, banking or community supports was particularly difficult for older people with hearing loss. Many of these services could only be accessed via phone calls or online services during the restrictions, pathways that were not accessible to many of these people. Typically these services would be accessed in person by those who struggled on the phone. These barriers inevitably resulted in increased risk and vulnerability. There is little doubt that the many spontaneous acts of kindness by neighbours and local community groups to check in on older people who could not reach out themselves undoubtedly saved many lives during the Covid-19 restrictions.

3.3.3 Online video technologies such as Facetime, Zoom and Skype became a vital means for many families and friends to stay in touch during Covid-19 restrictions. However, people with disabilities and older people are more likely to live in poverty and less likely to have access to internet or use digital technologies. As a result the impact of Covid-19 restrictions was more severe for these groups, and all the more so for those who are Deaf or Hard of Hearing and unable to use traditional technologies such as a telephone.

3.4 **Impact of face masks on Deaf and Hard of Hearing people.**

3.4.1 Many Deaf and Hard of Hearing people rely on lipreading to a greater or lessor extent to support communication – the number is in the hundreds of thousands in Ireland. Facial expression is also a core element of sign language vocabulary and grammar. The increased use of face masks in the community due to Covid-19 has created significant communication barrier for tens of thousands of Deaf and Hard of Hearing people, and this has contributed to increased feelings of isolation and being 'left out'.

3.4.2 The increased use of face masks has made a visit to the shop, the chemist or GP much more problematic for a Deaf or Hard of Hearing person. Such everyday situations have become much more stressful, embarrassing and potentially high risk if the person is not getting the right information. In one recent (hopefully exceptional) health consultation in a major hospital a Deaf woman was provided with blood test results by healthcare personnel wearing face masks with no sign language interpreter present. The woman was unable to understand anything that was said to her and was provided with a sheet detailing blood test results indecipherable to her. She left the hospital highly distressed and not knowing if her serious health condition was still in remission or had returned. The introduction of the CARDMEDIC communications tool to healthcare settings could greatly improve communication between healthcare workers and patients with hearing or sight loss (see www.CARDMEDIC.com).

3.4.3 Chime supports the use of transparent face shields as an alternative to face masks for use by the public. Face shields have a number of advantages over face masks, including allowing for sight of facial expressions and lipreading. There is expert opinion in favour of their use by the public. Although we have endeavoured to raise these matters with NPHET over a number of weeks, we have been unable to get any direct engagement from them. At this point in time, the Government have announced that face coverings will be mandatory from June 29th on public transport – but they have not yet published guidance on how this will be enforced or what exemptions will apply. This lack of clarity adds to the stress and confusion experienced by many members of the public, not least those who are Deaf and Hard of Hearing. For those who rely on lipreading, face coverings make this impossible and contribute to communication barriers and a sense of being 'cut off'.

3.4.4 In a small number of cases known to Chime, a Deaf or Hard of Hearing person with additional health needs may be availing of Personal Assistant (PA) services. Communication between the service user and the PA who must wear PPE and a face mask becomes very difficult and distressing in some of these instances. The provision of additional assistive technology has been helpful in some cases.

3.4.5 In a small number of cases, employees who are Deaf or Hard of Hearing have been impacted greatly in their workplace by the increased use of face masks. For example, Chime is aware of a number of healthcare employees who rely on lipreading to assist with communication in the workplace. The new regime in relation to PPE has created major communication difficulties for these workers and their colleagues. It is hoped that transparent PPE equipment will become available sooner rather than later to assist in these particularly challenging scenarios.

3.5 **Impact on access to general services for Deaf and Hard of Hearing people**

3.5.1 The Covid-19 restrictions created additional barriers for Deaf and Hard of Hearing people in accessing general services. Many essential services were only accessible online or by phone, e.g. banking and takeaway food. This greatly disadvantaged many older persons who are more likely to live alone and less likely to use online or digital services.

3.5.2 On a positive note, the Irish Remote Interpreting Service (IRIS) remained operational throughout the period, with ISL interpreters working from home. This provided a lifeline for many members of the Deaf community to enable them to conduct essential personal business. Also, the HSE expanded access to IRIS for GP appointments to all of the Deaf community – a welcome development that addressed a clear inequality in access to healthcare. The arrangement whereby IRIS interpreters worked from home actually increased the volume of available ISL interpreting, and should be continued indefinitely to help address an acute shortage of ISL interpreters.

4.0 **Impact of Covid-19 on parents and carers**

4.1 Up to 40% of Deaf and Hard of Hearing children have additional needs. The closure of schools and the loss of specialist supports for children with significant additional needs placed a considerable additional burden on parents and families. In some cases children's development and progress has been compromised by the disruption to education and support services – adding considerably to the stress and anxiety of parents. It is vital that these children and families have these services and supports restored to them as soon as possible. Alternative pathways for service provision should be developed with urgency if 'traditional' services and supports cannot be delivered in the short term.

4.2 There are a significant number of parents around the country who are carers for their adult Deaf children who have additional needs. In many cases these Deaf adults were unable to access Deaf support groups during the Covid-19 restrictions – meaning they had little or no access to communication in ISL during this period. This added considerably to the stress and anxiety experienced by both parents/carers and their adult children.

5.0 **Impact on Chime and service provision**

5.1 Chime provides a range of service on behalf of the HSE through a series of Service Level Agreements (SLA). Chime is a Section 39 organisation, and similar to other Section 39 organisations the funding from the HSE does not cover the full cost of the services provided under the SLAs. Chime raises approximately one third of the costs (c€2m each year) through a combination of social enterprise and fundraising. To date, during the period of the pandemic this funding has been reduced by approximately 70%. Other organisations have had similar experiences, and this is resulting in serious additional financial pressures that requires State support if essential services are to be maintained.

5.2 Additional costs for Chime associated with Covid-19 included PPE for staff, adaptations and equipment to enhance infection control in centres prior to reopening, and ongoing measures to ensure optimal hygiene and infection control for service activities. Total additional costs to date are in excess of €10,000.

5.3 Like many other voluntary organisation, Chime continued to provide support services to its service users during the restrictions. Most of these services were provided remotely, with some face-to-face visits for those most distressed and isolated. Additional IT investment was required to enable staff to provide these services, adding to the cost burden on the organisation. However, Chime was unable to continue it's social support groups during this time due to public health guidance. These support groups act as a lifeline to social interaction and inclusion, often providing the only socially accessible experience for members who communicate in ISL. The people who rely on these social groups were greatly impacted by the increased isolation and distress they experienced during the Covid-19 restrictions. Chime's social work team also reported increased levels of stress and anxiety for a significant number of clients and there has been a

number of personal tragedies within the Deaf community in recent times. It is imperative that access to the full range of mental health supports is made available to members of the Deaf community who need them, and that the specialist deafness mental health service to be provided by the HSE becomes fully operational without further delay.

6.0 **Summary of key recommendations**

6.1 Ensure all public information announcements are accessible to all in a timely fashion, and all Government and Public Health briefings to be broadcast with ISL interpretation (Section 2.2.1).
6.2 Ensure all public health and public service initiatives are accessible through the adoption of universal design principles, including those designed during emergency periods (Sections 2.2.1, 2.2.4).
6.3 Make personal assistive technology provided in schools to Deaf and Hard of Hearing children available to children and parents for use in the home environment (Section 3.1.3).
6.4 Develop online health and educational service supports for children and parents/carers to compliment and enhance face-to-face services and ensure continuity of service during any future emergency periods (Sections 3.1.4, 4.1).
6.5 Designate core elements of audiology services as 'essential services' during future emergency periods and ensure a consistent national approach to service provision (Sections 3.2.2, 3.2.3).
6.6 Provide access to assistive technology to older people with acquired hearing loss to support communication and alleviate social isolation (Sections 3.3.1, 3.4.4).
6.7 Implement the CARDMEDIC communications tool in all healthcare settings (Section 3.4.2).
6.8 NPHET to consider including face shields as an acceptable face covering for members of the public who struggle to wear a face mask due to communication or health issues (Section 3.4.3).
6.9 Provide laptops and software to facilitate ISL interpreters to work remotely from home, thus creating extra interpreting capacity for the Deaf community and service providers (Section 3.5.2).
6.10 Provide additional financial support to charities who have lost revenue and are providing services on behalf of the State to ensure essential support services are maintained (Section 5.1).
6.11 Ensure that the Deaf community have access to the full range of mental health services and supports (Section 5.3).

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