

# Chime Advocacy Newsletter

No. 1 Summer 2021

**Chime is the National Charity for deafness and hearing loss. Since 1964 we have championed the rights of Deaf and Hard of Hearing (DHH) people in Ireland.**

**Chime's Advocacy Newsletter aims to inform key stakeholders, including public representatives, of the priority issues affecting DHH people that Chime is currently advocating on.**

**The newsletter provides an overview of why the priority issues are important, what progress has been made to date, and the next steps in our campaigning efforts.**

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Brief updates

Want to know more? Something on your mind? Get in touch with us.

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**CARDMEDIC®**



Progressing  
Disability  
Services  
for Children  
& Young People

Working together to support children and families



Comhairle, Pobal agus Riosnaíocht  
Environment, Community and Local Government



**National Housing Strategy for People  
with a Disability  
2011 - 2016**



## **Irish Text Relay Service**

Helping people with hearing disabilities to  
make and receive calls



## Progressing Disability Services – the need for specialist services for Deaf children

Progressing Disabilities Services for Children and Young People (PDS) is changing the way disability support services are being provided across the country, with the aim of making access to services more equitable and fairer to all. Unfortunately, until a specialist team is put in place for deaf children, equity and fairness will not be achieved for them.

Why? Because clinicians working in primary care and community disability network teams do not have the essential competencies and expertise to assess the needs of these children (see panel). A PDS Advisory Group Report (2017)<sup>1</sup> recognised this, stating that many of these children are given a non-specific diagnosis that prevents them from getting the supports and interventions they need. In some cases there are missed diagnoses and in others there is misdiagnosis. The case studies give an indication of the lifelong damage that can result.

### KEY CHALLENGES FOR CLINICIANS ASSESSING DEAF AND HARD OF HEARING CHILDREN:

- Interpreting results when using assessment tools not normed on DHH children.
- Understanding the learning experiences of DHH children, identifying limitations and assessing the impact on their development.
- Assessing a child within the complexity of their individual communication experiences, which may include a combination of sign language, gesture, spoken language and assistive technologies.
- Assessing the complex interaction between deafness and additional needs, especially where these additional needs impact on communication, e.g. ASD, learning disability, psychotic illness, SPD, ANSD etc.
- Developing a level of expertise in working with a cohort of children with low-incidence needs.
- Identifying appropriate interventions post assessment to address the child's needs. ■

## Case Studies

### CASE STUDY 1: SEÁN

Seán is a 13 year old deafblind boy born with a rare genetic disorder. His experience was with services was highlighted in detail in the Irish Times on April 27th 2021. Seán and his family struggled to access services at times. As he got older Seán's behaviour became more challenging. He was referred to CAMHs, but a psychologist in the CAMHs service diagnosed him as having a moderate learning disability, and as a result CAMHs refused to see him.

Martha, Seán's mother said: **"I have met people with a moderate intellectual disability and this isn't it, it's mild. But this is the problem when you have someone with a dual diagnosis and your child is being assessed against someone who is hearing."**

Martha has paid for Seán to see a psychiatrist privately, who assessed Seán as having ADHD and prescribed him some medication. This greatly improved Seán's behaviour and concentration at home and in school, according to his mother.

### CASE STUDY 2: MARY

Mary (not her real name) developed disturbing behaviours in her early teens. She was referred to CAMHs who assessed her and concluded that her behaviour was due to poor parenting. They interviewed Mary with no sign language interpreter present.

Mary continued to struggle for a number of years with her behaviour and mental health. She was hospitalised on occasions due to self-harming. Chime arranged for a UK Child Psychiatrist specialising in deafness to assess Mary, but both local disability services and CAMHs refused to engage with him. Chime's own Adult Psychiatrist assessed Mary shortly before her 18th birthday and confirmed that she had a psychotic illness.

Mary is presently linked in to local adult community mental health services, is unemployed, socially isolated and continues to have significant mental health difficulties. Research confirms that timely diagnosis and treatment of psychosis is critical in achieving positive outcomes for individuals. Sadly, the delays in this case have resulted in lifelong consequences for Mary.

<sup>1</sup>: PDS Report of National Advisory Group on Specialist Supports for Deaf Children (HSE, 2017).



Chime is hopeful that progress can be made in the near future. Minister for Disabilities Anne Rabbitte has been supportive of Chime's efforts to get a specialist team for DHH children established as part of PDS, and there has been positive engagement from the HSE's newly established National Clinical Programme for People with Disability.

Research soon to be published by Dublin City

University<sup>2</sup> will highlight that DHH children are four times more likely to be at risk of social and emotional difficulties compared to hearing peers.

Chime will be engaging with all stakeholders to ensure that funding for this critical service is included in Budget 2022 and is a priority action in next year's HSE's Service Plan so that Deaf and Hard of Hearing children can get the care and support they need. ■

## A Home of Choice for Deaf people

Ireland is still grappling with the legacy of institutionalising people with disabilities. Ten years on from the report *Time to Move On from Congregated Settings (TTMO)*<sup>3</sup>, many people with disabilities continue to live in congregated settings or other inappropriate placements. The TTMO Report outlined a new national policy where people with disabilities would be supported to live ordinary lives in ordinary places. They would have choice and control over where and with whom they lived.

However, while Deaf people seek to live in ordinary places like everyone else, they were left behind following the publication of the TTMO Report.

### DEAF PEOPLE AND TIME TO MOVE ON REPORT

Most Deaf people can live independently and have choice and control over where they live and with whom. However, some Deaf people, just like some hearing people, need support to live in the community and may need the support of a residential service. However, in many cases these Deaf people live in residential settings where they are the only Deaf person and the care support is not provided in Irish Sign Language. These vulnerable people are completely socially isolated in their own home, unable to communicate with staff or other residents.

While some Deaf people did move from institutional settings into a home based in the community in accordance with TTMO, they continued to be placed in residential services with hearing staff and hearing residents who could not communicate with them. These vulnerable

**Most Deaf people want live in ordinary places just like hearing people and Deaf people who are fully independent choose to live on the same streets as everyone else. In other words, Deaf people don't choose to live on a street where there are only Deaf people!**

**However, they often choose to live with other Deaf people, and it is quite common for Deaf people to have a Deaf partner. This makes sense: relationships are based on communication!**

Deaf people live their daily lives adrift of the most fundamental aspect of human life: communication.

Despite a HSE Working Group Report in 2015<sup>4</sup> identifying 165 Deaf individuals in need of some level of accommodation supports and making a series of recommendations to provide such supports through ISL, little has changed for most of these people.

In January 2021, after many years of campaigning, Chime opened a community home for 3 Deaf women. The language of the home is ISL, and the residents are already thriving in an environment where they have access to the key ingredient essential for personal growth: communication. This new support service was established with funding from the HSE after a Deaf woman took a High Court action claiming her placement in a nursing home did not meet her needs.

<sup>2</sup>: Mathews, E. Psychosocial Development in Deaf and Hard of Hearing Children (In press).

<sup>3</sup>: Time to Move on from Congregated Settings (HSE, 2011).

<sup>4</sup>: Working Group Report on the Residential Needs of Vulnerable Deaf Adults (HSE, 2015).



## MILESTONES TOWARDS A HOME OF CHOICE FOR DEAF PEOPLE

### 2008 – 2020

Chime lobbied continuously on this Human Rights issue with a range of stakeholders.

### 2015

The HSE established a Working Group to assess the Residential Needs of Vulnerable Deaf People. 165 Deaf people identified in need of a range of supported accommodation with support services delivered through ISL.

### 2018

A Deaf woman residing in a nursing home took a High Court case stating that she was socially isolated and virtually living in solitary confinement. She lived in the nursing home for 4 years – even though she was only aged in her 30s.

### 2020–2021

Chime and the HSE agreed to establish a pilot supported accommodation programme for 3 Deaf people in Dublin.

St Joseph's Home for Deaf People in South Dublin, a congregated setting where there were over 30 Deaf residents, began moving residents to community settings with support provided in ISL, consistent with the TTMO Report.

## CURRENT CONCERNS:

- Over 100 of the 165 Deaf people identified in the 2015 Working Group report remain without the community services and supports recommended.
- Over 30 remain in inappropriate residential placements without access to communication in ISL.
- Most remain socially isolated in the community, many still living with elderly parents, with no plan and little hope for the future.
- A small number of these people are currently placed in a residential service for Deaf people in Northern Ireland. The service provider (a UK Deaf organisation) has announced it will be ceasing providing residential services – leaving these Deaf citizens in a very precarious position.

## SUMMARY

Some progress has been made. There is now a small number of Deaf people with support needs who are living successfully in the community, with support provided in ISL.

However, for the majority of the 165 Deaf people identified in the Working Group Report, little has changed. A new concern is that the 5 Deaf Republic of Ireland citizens currently living in a service in Northern Ireland face an uncertain future.

The Disability Act, the Irish Sign language Act and UNCRPD entitles these Deaf citizens to a home where they can communicate and be empowered to live a life of their choosing.

Chime will be working hard in the coming months to continue to highlight the needs of these vulnerable citizens. ■

## Access to affordable hearing aids for all people

In March 2021 the World Health Organisation (WHO) shone a light on the burden caused by unaddressed hearing loss in the world today. They published a 'World Report on Hearing'<sup>5</sup>, highlighting the increasing numbers of people with hearing loss across the globe and calling on Governments to put in place strategies to treat unaddressed hearing loss in their populations.

The WHO said this made ethical and economic sense: they estimated that Governments could expect a return of almost €16 for every €1 invested in ear and hearing care over the following 10 years. Investment in hearing health results in a significant cost benefit because unaddressed hearing loss has a pervasive impact on people's lives.

<sup>5</sup>: WHO World Report on Ear and Hearing Care (WHO, 2021).



## LOW UPTAKE OF HEARING AIDS

Ireland is an outlier in Europe in terms of the low uptake of hearing aids in our population. The Irish Longitudinal Study on Ageing (TILDA) found that only one in five older people with hearing loss in Ireland have the hearing aids they need, while we prescribe hearing aids at approximately half the rate per head of population compared to the UK, Germany, France, Norway, Spain and the Netherlands (EHIMA, 2016-2020)<sup>6</sup>. Cost is a key factor, as medical card holders with hearing loss, who are entitled to free hearing aids from the HSE, are twice as likely to have a hearing aid as those who don't have a medical card and must purchase hearing aids themselves (TILDA 2017)<sup>7</sup>.

**“Hearing loss if unaddressed, can impact negatively many aspects of life: communication; the development of language and speech in children; cognition; education; employment; mental health; and interpersonal relationships. (WHO, 2021)<sup>5</sup>”**

## KEY FACTS ABOUT HEARING LOSS IN IRELAND

- According to the HSE, 8% of the adult population need hearing aids – that's 300,000 people.
- Only one in five have the hearing aids they need (TILDA, 2017)<sup>7</sup>.
- People with a medical card are twice as likely to have a hearing aid (TILDA, 2017)<sup>7</sup>.
- There are currently 20,000 people on audiology waiting lists<sup>8</sup>, with some waiting three or more years for a first appointment.

## POSITIVE NEWS

Chime has been advocating for many years for better access to hearing aids for people with hearing loss in Ireland. This included presentations to an Oireachtas Committee and meetings with the Minister for Social Protection. Eventually an important change was made to the hearing aid grant in Budget 2021. The previous grant limit of 50% towards the cost of a hearing aid grant was removed, and this means that people can now claim the full cost of hearing aids up to the grant maximum of €1,000, effective since the end of March 2021.

## 34% INCREASE IN HEARING AID UPTAKE

Since the new grant arrangements came into effect 3 months ago, there has been a 34% increase in the numbers of people applying for the grant compared to 2019. This means that an extra 1500 people have accessed hearing aids.

This is a good start, but there is still a way to go in addressing the low uptake of hearing aids in Ireland. We need to address the stigma associated with hearing loss, improve referral pathways and build awareness amongst stakeholders of the importance of early treatment of hearing loss as recommended by the World Health Organisation. ■

**A Lancet Commission (2017)<sup>9</sup> estimated that up to 9% of dementia is preventable through the early treatment of hearing loss – this would equate to an annual saving of over €80m in Irish healthcare costs.**

<sup>6</sup>: European Hearing Instrument Manufacturers Association. Market Statistics Reports (2016-2020).

<sup>7</sup>: Health and Wellbeing: Active Ageing for Older Adults in Ireland (TILDA, 2017).

<sup>8</sup>: National Audiology Waiting Lists (HSE, Sept 2020).

<sup>9</sup>: Dementia prevention, intervention, and care. (Lancet Commission, 2017).



## Some updates in brief

Below in brief are some other initiatives Chime is currently advocating on to reduce barriers and improve the lives of Deaf and Hard of Hearing people.



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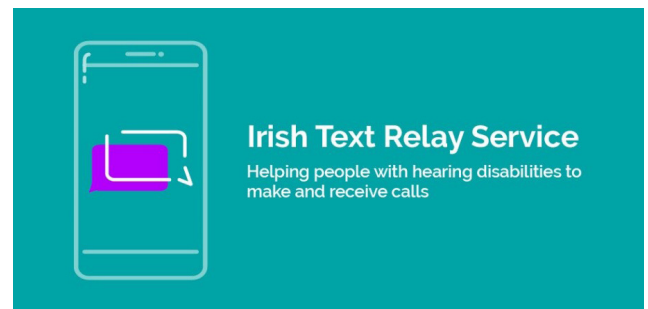
### CARDMEDIC

CardMedic is a communication tool designed to improve the transfer of vital information between healthcare staff and patients. It works across any barrier – whether visual, hearing or cognitive impairment, foreign language or PPE. It uses a series of flashcards presented on a smart device such as a phone or tablet to present information to patients on procedures and interventions as required. It is available in many languages, including British Sign Language, and is also available in audio format for people with visual impairments.

Dr Rachel Grimaldi, a radiologist developed the concept of Cardmedic when she saw patients struggling to communicate with healthcare staff wearing PPE following the onset of the pandemic in 2020. Many Deaf and Hard of Hearing people struggle when communicating with healthcare staff wearing facemasks. Chime is currently engaging with the HSE to explore introducing CardMedic to Irish healthcare settings.

**In one UK hospital the use of CardMedic resulted in a 28% improvement in patient confidence and a 95% improvement in understanding healthcare staff wearing PPE.**

For more information see [www.cardmedic.com](http://www.cardmedic.com)



### TEXT RELAY SERVICES

Text relay services allow people who cannot make voice calls to make phone calls in real time via a relay operator. The service benefits Deaf people, people who have been deafened, and those who have speech difficulties.

Currently all major telecom providers must provide access to this service to customers under a EU Directive. The Irish Text relay Service (ITRS) is operated on their behalf by Eir. However, the service is poor and awareness is low – so most of the people who could benefit from the service are unaware that it exists!

Chime is currently lobbying the Department of Communications, ComReg and Eir to upgrade the service so that it is on a par with the equivalent service in the UK, and to increase awareness so that more people can benefit from it.

More info on ITRS here: [www.itrs.ie](http://www.itrs.ie), but for a better understanding of text relay services visit [www.relayuk.bt.com](http://www.relayuk.bt.com) ■



The National Charity for  
Deafness and Hearing Loss

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