



## **National Advocacy Service for People with Disabilities Opening Statement to the Joint Committee on Disability Matters**

**7<sup>th</sup> October 2021**

Hello, thank you Chair and members for the opportunity to speak today. My name is Louise Loughlin, I am the National Manager for the National Advocacy Service for People with Disabilities. I am joined by Suzy Byrne our Greater Dublin Regional Manager.

We provide professional representative advocacy to adults with disabilities throughout Ireland, to ensure that their will and preferences are heard in decisions that affect their lives. In 2020 we provided over 3,700 advocacy interventions. This included over 1,000 individual cases. 7 in every 10 of these cases could be described as complex where the advocate helped with 2 or more issues. We also provided information, advice, and support in over 2,700 instances.

We host the Patient Advocacy Service, which was commissioned by the Department of Health. It provides independent, free, and confidential advocacy for people who wish to make complaints or about patient safety incidents in HSE-funded public acute hospitals or nursing homes.

We believe that living in residential settings such as congregated settings, group homes, nursing homes and mental health facilities can be a severe barrier to accessing community and cultural life. This point is illustrated throughout the *"Time to Move on from Congregated Settings a Strategy for Community Inclusion"* report published by the HSE in 2011.

We welcome the refreshed commitment for decongregation made in the Programme for Government. Decongregation means the movement of people with disabilities from congregated settings to homes in the community with the necessary supports. This allows people to live more independently and become more involved with their community.

Advocacy can play a crucial role in ensuring that such transitions are person-centred. Our work is particularly significant given the additional barriers to community inclusion and engagement that people with life histories of institutionalisation may experience, and the stigma sometimes attached to being a person living with a disability.

However, we have noticed a trend in a slowing down in the closure of congregated settings. We have also noted that the issues associated with these settings have been compounded by Covid restrictions.

Visiting restrictions meant that people living in services had prolonged periods without access to their communities or face-to-face contact with friends or family. People have told us that they had feelings of isolation, loneliness, and anxiety.

Even the vaccine rollout impinged on people's community participation. In some cases, family members sought to prevent the disabled person from receiving the vaccine. Our work ensured the

person received their vaccine. This meant that they could become more involved in community life as public health restrictions were lifted.

Some residential services have rigid schedules. This can be due to issues like staffing and resourcing. But for the person living there, it may mean having to eat food at a certain time, having strictly enforced sleeping schedules, and a lack of access to transport. This results in limitations on participation in community and cultural life.

We aim to empower people to become active participants in decisions about their own lives and decision making. This is in line with both the Assisted Decision-Making (Capacity) Act 2015 and the UNCRPD. We look forward to the full commencement and implementation of the Act next year, and the Decision Support Service going live.

There is a financial cost to attending cultural events, engaging in the community, and participating in public life. In 2020, 12% of our cases were about finances. People with disabilities sometimes find that family members and carers are overly controlling of how they spend their money. We have experience of cases where people still cannot access their own bank account, are not consulted on how their estates are managed, residential services seeking information about why a person is accessing their funds, and not having sufficient funds left for social activities after paying for nursing home charges.

Important facilitators to accessing community and cultural life are home support and personal assistance services. There is no statutory provision for either home supports or PA services. Access depends on geography. There should be a standardised national system to ensure everyone has equal and fair access to these supports. We welcome the current consultation by HIQA on the development of Draft National Standards for Home Support Services. This should also be extended to PA services.

We ask the Committee to recognise that this lack of support and consequent lack of autonomy for a disabled person directly contravenes the UNCRPD article to enable active participation in the community. It may prevent disabled people from becoming involved in public life or cultural events. Whilst we recognise the reasons behind this are complex, we urge this Committee to recommend that all care and support services are resourced and supported to ensure that that all people availing of their services can live their lives as fully as possible.

Finally, we thank all the members of the Committee today for their commitment to disability matters and we would welcome the opportunity to provide more information about our work in the future. We are also launching our suite of "Advocacy Matters" reports on October 20<sup>th</sup> where we will highlight in more detail the impact of Covid on the people we advocate for and you are all welcome to attend.