



Joint Committee on Disability Matters. March 9th 2023

Inclusion Ireland Opening Statement

1. Good morning.
2. My name is Derval McDonagh and I am the Chief Executive Officer of Inclusion Ireland. I would like to sincerely thank the committee for inviting Inclusion Ireland to this session today.
3. I am joined by my colleague Una Coates who is an advocate and spokesperson for Inclusion Ireland. I will hand over to Una to share her thoughts on advocacy and self-advocacy in a moment.
4. At Inclusion Ireland, 1/3 of our board have a lived experience of intellectual disability. The directors regularly share their experiences around the challenges of self-advocacy and the lack of understanding around the need for training, mentorship and support so that people can advocate for themselves and also advocate in collective spaces with other disabled people.
5. The language around advocacy can sometimes be misunderstood. "Self-advocacy" and "self-advocate" are terms that are commonly used within the community of people with an intellectual disability. In 2015 and 2016, Inclusion International undertook a worldwide survey of people with an intellectual disability and wrote a Global

Report on Self Advocacy for Inclusion.¹ In this document they outline what “self-advocacy” means:

6. *Self-advocacy is about having a voice (even when we cannot speak); being listened to and taking control of our own lives. Self-advocacy is about growing our confidence and belief in our abilities. Self-advocacy is about knowing our rights and that we must be included in all parts of community. Self-advocacy is about working together to make change in our communities.*²
7. Progressive stages of self advocacy are mapped out from “personal empowerment and building confidence”, through “peer support and self-help”, towards the more collective approach of “advocacy for action”.³
8. Currently Inclusion Ireland and the Independent Living Movement Ireland are working together on developing a guide for the participation of disabled people in HSE services. There has been a lot of learning in working together. A working definition for self-advocacy we agreed recently states that:
9. *We recognise that disabled people (regardless of impairment) often need additional supports in order to build their capacity and confidence. This work is based on identifying individual issues but also specific supports to participate in group discussions with other disabled people or to participate in representative spaces. Self-advocacy not only refers to disabled people being supported to advocate on issues they face as individuals, but also being facilitated to work collectively with other disabled people. It is our shared belief that at the core of effective participation is disabled people working collectively together.*

¹ <https://inclusion-international.org/wp-content/uploads/2016/11/Global-report-on-self-advocacy.pdf>

² Ibid, p.4

³ Ibid p15 and 16

10. Often when we talk about self-advocacy people assume we are only speaking about people who use verbal language to communicate. We cannot leave people with higher support needs out of the conversation. Some of the best advocates we have ever met are nonverbal, have high support needs and can tell you exactly how they are feeling with one gesture or facial expression. Advocacy cannot be a solo effort; advocacy is about relationship. Some people with intellectual disabilities may find it challenging to express verbally what they want or need, but can express in many other ways, if there are willing partners who take the time to build that relationship and really listen.
11. Learning to speak up for yourself is the first step in having control over your life. Too often people with intellectual disabilities have had no control over their lives with decisions big and small being made for them by others.
12. We know that there are many people with intellectual disabilities throughout the country in situations they did not choose or have any say over. This includes the 2400 people living in congregated settings, people living in nursing homes and thousands of people living at home with their families with no hope of moving out into a life and a home of their own. At inclusion Ireland when we hear terms like “underrepresented” or “hard to reach” we challenge that kind of thinking. It is society which has created these conditions. People themselves are not hard to reach, we have created the barriers which exclude, ignore, devalue and overlook people. This exclusion has led to the creation of oppressive systems such as institutional living.
13. The proper resourcing of advocacy and developing systems where the voice of the person is prioritised is the only way to unpick the years of segregation and institutional thinking.

14. In the 80's and 90's community development projects began to support women to meet in groups and do personal development and assertiveness training. This groundwork started conversations about women's rights that were very important in advancing gender equality in Ireland.
15. A similar investment now needs to take place to advance the disability equality and equity agenda. In line with the UNCRPD, the state needs to invest in capacity building supports for advocacy and it needs to support the development of DPOs where disabled people can advocate for changes in policy and practice that will advance these rights in Ireland.
16. Inclusion Ireland will continue to support people to develop the skills they need to speak up for themselves and to be a part of collective spaces and DPOs. It is only by working together that we will see the systemic change so badly needed.
17. I will now hand you over to Una Coates who will give her part of our opening statement .

18. My name is Una Coates.
19. I am the chairperson of Inclusion Ireland's Self Advocacy Committee.
20. I am proud to be here as a woman with an intellectual disability to speak up and use my voice.
21. Ireland ratified the UNCRPD in 2018.
22. Article 4.3 of UNCRPD talks about consulting with and making sure people with disabilities are involved in decisions that are important to them, including laws and policies
23. I did a course on self advocacy in 2018. It was the start of my journey in speaking up for myself.
24. Advocacy is when other people speak on behalf of a group.
25. Self advocacy is when people speak up for themselves about what is important.
26. It is powerful to hear people tell their own stories. Only people with intellectual disabilities can tell you what it is like to have their experiences in life.
27. As a committee, we organise events, we do focus groups to hear what people have to say and we help to make information easy to read.
28. We take part in consultations too. Our committee has both men and women and we are all the same.
29. To make informed decisions we need information in a way we understand. We need more easy to read information and videos and for people making laws and policy to understand that we all communicate in different ways.
30. People can have their voice heard even if they don't speak, they can use technology or have a communication partner to get their message across. I am lucky I can speak and I will speak for others. We are all equal no matter how much support we need. We all have the same rights.

