**Summary of the Listening Session, ‘Awareness Raising’**

**June 2023**



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# Introduction

On 24th May 2023, the National Disability Authority (NDA) hosted an online listening session to hear directly from disabled people and their representative organisations on the theme of ‘Awareness Raising’. The theme of this session is based on Article 8 of the United Nations Convention on the Rights of People with Disabilities (CRPD).[[1]](#footnote-1) The CRPD is composed of Articles which address different themes, setting out what States need to take action on to ensure that disabled persons enjoy all their human rights. Article 8 outlines how States should go about awareness raising of disability issues and the barriers to full social participation that still exist.

The aim of the session was to listen to the lived experience of awareness raising and the suggestions of disabled people on how to make communities and society more aware of the issues facing disabled people. The learning from the event will inform NDA advice and information to the Minister, department officials and the wider public sector. The learning will also inform Ireland’s UN CRPD implementation plan that is to be developed during 2023.The listening sessions are also an opportunity for disabled people and DPO’s to hear from each other.

Twenty seven participants attended, the majority of whom had a disability. In addition, eleven NDA staff attended. The first part of the listening session featured keynote speakers with lived experience of disability addressing issues around awareness raising. The speakers were:

* Adam Harris, CEO, AsIAm
* Paula Soraghan, Development Worker, Independent Living Movement Ireland (ILMI)

After the keynote speeches, the speakers answered questions from the attendees. This was followed by a more indepth discussion on the topic with a small group of participants with an NDA facilitator and note taker. The event concluded with the note taker providing a summary of the discussion including the experiences and suggestions expressed by the participants in the group.

This report summarises the keynote speeches, questions and answers and the discussion session. It is comprised of paraphrasing what was said on the day, with occasional direct quotes to clearly reflect the voices of disabled people. It will be shared with Anne Rabbitte T.D, Minister for State with responsibility for disability, with the officials in the Department of Children, Equality, Disability Integration and Youth. It will also be sent to those who participated in the event and will be published to the NDA Website.

# Summary of the Plenary Presentations

## Adam Harris, AsIAm

As the first keynote speaker of the day, Adam Harris addressed some issues around disability awareness. Some of his main points on the day were:

* That awareness raising is central to the overall rights based approach and that many of the barriers come from a lack of understanding amongst peers and amongst the general public. There is a lack of understanding amongst services that people should have parity of access.
* AsIAm are trying to move away from the term awareness raising. Not moving away from the concept but moving away from what awareness raising has been in practice, which is sometimes tick the box and sometimes lots and lots of talk but not enough action. It is an important starting point, but it is not a destination.
* The AsIAm Same Chance report published in 2023 provides a summary of insights from 1,600 autistic people, parents, family members and carers.[[2]](#footnote-2) The results found that 80% of respondents say they are aware of autism as a clinical condition, 40% say they have a family member who is autistic and more than half say they know somebody who is autistic.
* When asked to pick social traits to autism in those that know an autistic person, people are much more likely to point to positive attributes.
* 20% of people still think the most reliable source of information about autism is from social media. Young people aged 18 to 25 have more progressive attitudes and that shows the broader benefits of inclusive education for society.
* Many people are seeing autism more generally as a normal part of diversity. Interestingly, the Irish public recognise the barriers that autistic people face and indeed there is a distinct difference between what the Irish public report and what the autistic community experience is on a day-to-day basis.
* The Same Chance survey found that 90% of respondents did not believe That people in the community knew enough about autism, 91% said being autistic was a barrier to gaining friendship, 84% didn't feel social gatherings and occasions were made accessible or open to autistic people, 68% felt they are were treated differently and 80% said they had to hide the fact they were autistic.
* With regard to family life 57% of people said they did not feel that they had the level of support they needed from the broader family circle. Adam said, ‘I think it is really important for us as a community to create a space and opportunities for those conversations to take place.’
* An area of concern is language. Sometimes because people are not sure about language or terminology they simply disengage, and spaces need to be created in which people can have these conversations with confidence.
* The disability community have to be careful with awareness raising as it can consistently lead to stereotypes and in the disability community it is particularly important that intersectional voices are highlighted.
* The state has an important role to play in this with disability and autism still referred to inappropriately in official documents
* When thinking about awareness raising people sometimes make assumptions about what people need or know. When AsIAm asked other members of the autistic community what they wished that others knew about autism, they said they wished others would be friends and “stop treating us like we are invisible.”

## Paula Soraghan, Development Worker, Independent Living Movement

Paula was the second speaker on the day, and a summary of her main points are:

* There are approximately1400 to1600 disabled people under the age of 65 living in nursing homes. This is unacceptable and it needs to change, it means people are not realising their full potential and do not get to live lives of their choice.
* Disabled people have no right to a personal assistance service. Over the last year or so, ILMI launched a big campaign to highlight the issue that personal assistance is not a right and it is not written into law. It is very much done on a piecemeal basis and it is a post code lottery based on where you live and how well you can advocate for yourself. It is not a right.
* A DPO is a Disabled Persons Organisation, an organisation that is led and directed and governed by disabled people. They are focused on rights and equality and on challenging the barriers that face disabled people and removing these barriers. They work to make life real so that every disabled person in Ireland lives the life of their choosing and there is also the fair value and meaningful participation of disabled people.
* All government policies and strategies require meaningful consultation with DPOs. Consultation must go beyond a tick box exercise and should be the starting point not the end point.
* The social model of disability is key in people being aware of the barriers they face and DPOs can change this because there is still very much the dominant belief that disability is a deficit.
* Disabled people are the experts in their own lives. They need to be given the opportunity to have the space to share their experiences and have their voices heard. Empowering disabled people with the knowledge of the social model and working together with a DPO can change attitudes by shifting the lens from a disabled person feeling like the reason he/she is facing so many barriers is because of their impairment and condition rather than the environment and that they don’t have to fight alone.
* Awareness raising can only be done by disabled people with lived experience so that it is genuine awareness raising and understanding. Society is aware that disabled people exist but there is not a deep understanding of the barriers they are facing and that actually being disabled is very much a political issue.
* IMLI challenge and raise people's expectation and that will look different for everybody but it is about letting people know everyone has a family and deserves a family and to make rights real for everyone.
* Intersectionality is important, for example a disabled woman who is a member of the LGBTQI community or disabled people of colour are people who have multiple identities. Disabled people are friends, they can be mothers and parents, they can be spouses, they can be employers, employees. It is important to look at the disabled person as the whole individual and being respectful of their experiences and what their impairment might bring with them but not letting that over shadow them. It is making sure everyone has reasonable accommodations.
* It is about moving away from disability awareness and very much focusing on disability equality and about challenging the unacceptable model of disability that says the disabled person has something wrong with them and therefore treating them as inferior.

There were several questions after the presentations. Adam was asked about changing trends in attitudes over time, whether teachers received disability equality training and a question in relation to breakthroughs in thinking in disability awareness

Adam responded by saying that representation was essential to inform attitudes and that autistic people sharing their experiences was a starting point for moving beyond stereotypes. With regard to teaching, he said that we need a much more diverse cohort of teachers to reflect Irish society in the 21st century and that disabled people are just another aspect – ‘To be it, I have to see it.’ Paula agreed emphasising that training is key and that it should be implemented in the very beginning.

In relation to breakthroughs in thinking in disability awareness, Adam pointed to increases in representation being an important element of increased awareness, ‘it is moving autism from something that was seen as rare to the reality that is part of the day-to-day.’ Paula added that the increased awareness of DPOs has been an important breakthrough and said, ‘DPOs need to be properly funded and properly resourced so we can have our voices heard and tangible social change can continue to happen.’

Paula was asked how ILMI are organising and recruiting new members. She responded that ILMI have a presence on social media and are always trying to get more visibility and be active as much as possible to grow their membership. She outlined that ILMI are working to break down barriers and stereotypes.

# Summary of the Discussion Group

Eight participants attended the discussion group. These included two participants representing two DPOs, and their responses are marked with an asterisk\* and their comments are presented first under each heading.

The themes addressed in the discussion group were:

* Issues relating to a lack of understanding of disability
* The role of disability awareness and disability equality training
* The portrayal of disabled people in the media

## Issues relating to a lack of understanding of disability

* Participants discussed the need for a massive national disability awareness campaign and how disabled people taking part in these campaigns can be a good and bad thing. There is a need for the personal living experience, but also a recognition that it can be harmful if disabled people need to be inspirational in order to create impact. They noted that people with disabilities do not want to have to expose details about their lives for the general public to understand what it is like to have a disability \*
* The group noted that the CRPD Article 4.3 is about consultation with DPOs. The group spoke about the CRPD, and the need for a better awareness and understanding of Article 43 and general comment 7 across all government departments and public sector organisations including the NDA and IHREC.\*
* The group noted that disability awareness has become more mainstream and most people think that all people with disabilities have access to services but this assumption is incorrect. There is a need to move beyond building awareness to achieving equality and an understanding of the living experience of disabled people.
* Participants also spoke of their experience saying that unless you have a disability or someone you know has one you do not know what it is like to have a disability.

## The Role of disability awareness and disability equality training

* The group noted that the funding for disability awareness and equality training is not going directly to DPOs and made the point that the DPOs should be directly funded to do this training.\*
* There needs to be broader training and awareness on what a DPO is\*
* One participant noted the difficulties in measuring the impact of disability awareness training and questioned the effectiveness of training mentioning the danger that employers and others would not implement what they have learned.\*
* Another participant said that the inclusion of children with disabilities in mainstream school and later in mainstream jobs would lead to a significant change in attitudes.
* There was broad agreement in the group that employers needed more training and specifically disability equality training rather than just awareness raising.

## The portrayal of disabled people in the media

* One participant noted that when the media are looking for comment on a disability issue, that they should approach a DPO rather than a service provider as this would give greater meaning to the experiences and stories that disabled people have to share.\*
* One participant talked about how radio theatre was a great form for visually impaired people and that more should be comissioned.\*
* Participants discussed the issue of representation in the media and noted that there was strong representation on social media but less so in mainstream media.
* Participants gave examples of disabled people who were successful in media but noted that there is more scope for disabled people to be involved in front of and behind the scenes.
* In discussing disabled characters on television, one participant noted, ‘there is a need to move away from disability being the storyline when disabled characters are involved. Disabled characters should just be part of the general storyline/plot, without a focus on the fact that they are disabled.’

## Conclusion

In summary, participants addressed the importance of a range of issues including the following:

* The need for a full and complete understanding of Article 4.3 of the UNCRPD and general comment 7 issued by the UN Monitoring Committee
* Increased and direct funding for DPOs to deliver training.
* Moving training beyond disability awareness to disability equality training
* Increasing understanding of what a DPO is, and what they do
* Increasing and improving representation of disabled people in the media
* Increasing funding opportunists for disabled writers

# Appendix A: Text of Article 8, CRPD

1. States Parties undertake to adopt immediate, effective and appropriate measures:

a) To raise awareness throughout society, including at the family level, regarding persons with disabilities, and to foster respect for the rights and dignity of persons with disabilities;

b) To combat stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas of life;

c) To promote awareness of the capabilities and contributions of persons with disabilities.

2. Measures to this end include:

a) Initiating and maintaining effective public awareness campaigns designed:

i. To nurture receptiveness to the rights of persons with disabilities;

ii. To promote positive perceptions and greater social awareness towards persons with disabilities;

iii. To promote recognition of the skills, merits and abilities of persons with disabilities, and of their contributions to the workplace and the labour market;

b) Fostering at all levels of the education system, including in all children from an early age, an attitude of respect for the rights of persons with disabilities;

c) Encouraging all organs of the media to portray persons with disabilities in a manner consistent with the purpose of the present Convention;

d) Promoting awareness-training programmes regarding persons with disabilities and the rights of persons with disabilities.

1. See Appendix A for full text of Article 8 [↑](#footnote-ref-1)
2. https://asiam.ie/same-chance-report-2023/ [↑](#footnote-ref-2)