**Summary of the Listening Session, ‘Improving participation and inclusion through creating liveable communities’**

**June 2022**



Contents

[Introduction 3](#_Toc107391453)

[Summary of the Listening Session 4](#_Toc107391454)

[Attitudes and community participation and inclusion 4](#_Toc107391455)

[Prioritising the participation of disabled people and DPOs 6](#_Toc107391456)

[Joined up thinking to improve personal supports and public services 8](#_Toc107391457)

[Accessibility and Universal Design 9](#_Toc107391458)

[Conclusion 10](#_Toc107391459)

[Appendix: Summary of keynote speakers on participation and inclusion 12](#_Toc107391460)

[Dr John Bosco Conoma, Director of the Centre for Deaf Studies, and Assistant Professor, School of Linguistic, Speech and Communication Science, Trinity College, University of Dublin 12](#_Toc107391461)

[Nicole Norton and Orla and Brendan O'Reilly 14](#_Toc107391462)

[Fiona Weldon, Independent Living Movement Ireland (ILMI) 16](#_Toc107391463)

**Note on terminology**: In this report, the terms “persons/people with disabilities” and “disabled people” are used interchangeably. The term ‘disabled people’ is recognised by many in the disability rights movement to align with the social and human rights model of disability, as it is considered to acknowledge that people are disabled by barriers in society and the environment. However, others prefer the term “persons with disabilities” because of the inherent understanding in the term that they are first human beings entitled to human rights. This reflects the language used in the UNCRPD. Finally, we recognise that some people who others might regard as having a disability do not identify as being disabled.

# Introduction

On 4th May 2022, the National Disability Authority (NDA) hosted a virtual listening session to hear directly from disabled people and their representative organisations on the theme of ‘Improving participation and inclusion through creating liveable communities’. The aim of the session was to listen to the lived experience of participation and inclusion and the suggestions of disabled people on how to make communities more inclusive and liveable. The learning from the event will inform NDA advice and information to the Minister, department officials and the wider public sector. The listening sessions are also an opportunity for disabled people and DPOs to hear from each other.

Twenty participants attended, the majority of whom had a disability. In addition, fourteen NDA staff attended. Two individuals who could not attend or attended only part of the session, sent written or oral submissions, which have been incorporated into this summary. The first part of the listening session featured keynote speakers with lived experience of disability addressing the issue of participation and inclusion:

* Assistant Professor, Doctor John Bosco Conoma, School of Linguistic, Speech and Communication Science, Trinity College
* Orla and Brendan O’Reilly from Dublin introducing their video on Independent Living
* Nicole Norton from Clare introducing her video
* Fiona Weldon, Independent Living Movement Ireland (ILMI)

The keynote speeches were followed by three parallel discussion groups each with an NDA facilitator and note taker. The event concluded with a participant from each discussion group synthesising the experiences and suggestions expressed in their group. This report summarises the discussions and inputs during the listening session. It is comprised of paraphrasing what was said on the day, with occasional direct quotes, and reflects only the voices of disabled people. There is no added commentary. It will be shared with Ms. Anne Rabbitte T.D, Minister of State with responsibility for disability, and with officials in the Department of Children, Equality, Disability, Integration and Youth. It will also be sent to all those who participated in the event and will be published to the NDA website.

This is the second NDA Listening Session. In 2021, the first listening session addressed the theme of Building Back Better post-COVID. In addition to the learning from the event, the summary report has been used extensively. NDA staff and others have quoted directly from it and cited it in their work, for example, in the ‘Lockdowns Unlock Innovations’ report[[1]](#footnote-1) and the forthcoming report on attaining participation and inclusion by creating liveable communities.

# Summary of the Listening Session

The main themes addressed in dialogue and discussion were as follows:

* Attitudes and community participation and inclusion
* Prioritising the participation of disabled people and DPOs
* Joined up thinking to improve personal supports and public services
* Accessibility and Universal Design

In addition, this report includes an appendix with a summary of the content presented by the keynote speakers.

## Attitudes and community participation and inclusion

* Participants discussed the need to be included in society, to feel part of and actually be a real part of the community. They considered how damaging low expectations were and the need to cultivate high expectations for disabled people and for every person.
* Participants considered how they would define community and offered the following ideas. Community means acceptance by people around you, it means not being ignored. It is all about the attitude of those around you. It means acceptance by local government of your rights and of them working professionally for the public, including listening and attending to the needs of disabled people so that they can fully participate in ordinary life in their communities.
* Participants spoke of how the ability of disabled people is phenomenal and they considered that what they can contribute to the community should be taught to and acknowledged by themselves as well as everyone else from a young age. They identified positive attitudes as key to building community and moving accessibility forward. One participant said: “I would like to see young people, young teenagers and young adults being taught more about disability and bringing disability awareness into schools and companies. Everyone needs to be aware that one cannot always see the disability. We need to be able to help people stop and think about the practical barriers that might be there for others, including disabled people”.
* Participants discussed how people should not be judged by the way they are born. They can’t help it as they don’t choose it. One participant said: “We are born into a society that doesn’t take into account that we cannot change the impairment but that society can change how they think about us”. Some felt that society often treats all people with disabilities as clients and patients. Disabled people need to show everyone the different roles that disabled people have just like everyone else, such as being professionals or care givers, looking after elderly parents or after their children etc.
* A participant, who is legally blind, shared some of his experiences such as people going in front of him in a queue in a shop thinking he doesn't know what's going on or being totally ignored. Another participant, whose son is a wheelchair user, reported facing barriers on transport, including attitudinal barriers even the attitude that “your son is taking up too much space”!
* There was a comment from a participant that terms like Special Olympics might be changed to, for example, extra support Olympics. “We are not special but just need a bit more support to do the same as others. We are like everybody else; we are equals”. This participant thought that fear is a major barrier, which comes from a lack of knowledge and understanding of disabled people and their issues. One participant who plays football felt that people with extra support needs don’t get the recognition that they deserve because of their needs: “There is an attitude that manifests itself when someone is discovered to have a hidden disability. Things change and they find they are left as substitutes even if they are better players.”
* A participant said that “There are psychological issues connected to physical limitations that are rarely discussed. It is important to be aware of these issues to prevent them or address them. Loss of independence, assumptions made about you, dependency, over-compensation, and body image issues. Confidence can get a hit. On the other hand, being sheltered/over protected as a child with a disability can give rise to confidence issues and there are a lot of restrictions that I think disabled people may unnecessarily impose on themselves or their families. At the same time, as someone with a disability, I think we can be more at risk in particular areas. For example, some may enter relationships and risk becoming co-dependent with their partner. Some can struggle having their partner become their carer. Others struggle with their partners acquired needs or changes in mood. Friends do too if they are honest. Abuse can be more accepted in relationships where dependency is an issue. Others, particularly those with learning difficulties may not fully understand the relationships they are entering into and can be taken advantage of as they seek love”.
* One participant spoke of his experience of students in post primary education with additional needs. He said that they can use disability labels as an excuse for lack of attempt. He wondered how much damage comes with using labels if they are not accompanied by concrete and personalised strategies and ongoing guidance. In his experience, a growing number of students are on medication, which impacts them and their learning in multiple ways. He gave examples of
* A student who regularly misses class time to receive treatment.
* Increasing numbers of students with treatment for anxiety disorders who refuse to come into school and take classes online most of the time if they can. They make no friends.
* Students who develop drug addictions due to being on medications from doctors for lengthy periods.

## Prioritising the participation of disabled people and DPOs

The following are some issues raised by participants in relation to participation.

* Participants spoke of the need for genuine participation starting at the planning level and the development of policies and continuing through to the evaluation and accountability stages post-implementation.
* Participants discussed how the UN committee has prioritised implementing CRPD Article 4.3, which is cross-cutting and fundamental. They considered that disabled people need to fill the civil space opening up to them through the CRPD but need resources to participate as per the CRPD. Adequate funding is required so that DPOs can operate effectively. There was a perception among some participants that the system seems to be biased against DPOs and that it needs to be overhauled. As per the CRPD, disabled people must be involved in drafting any policies and laws that impact on their lives. This means that they need to be sitting at the table - and not just one of them but many of them. It's about collective action to attain the right to participate. Service providers should not run advocacy services - there needs to be total separation. Similarly, the Oireachtas disability group who meet monthly should be a DPO. There should be no consultations without DPOs. Organisations are cutting off DPOs rather than consulting with them.
* A participant spoke about how crucial it is that "autonomous collective spaces" are created for disabled people.
* Participants discussed how the expertise of disabled people needs to be valued, their perspective understood and their needs identified. This is what is crucial rather than attempting to make them fit into a world that will never meet their needs. The lived experience of disabled people, and their experience of discrimination, unites disabled people regardless of their impairment. “Nothing will change if we keep letting non-disabled people talk for us not with us, no disrespect intended”. The disabled community need disabled people to become much more involved to get a power balance. “I don’t need anyone else to talk for me”. Disabled people are the right people to run organisations for disabled people. If a CEO or a manager is not disabled, they must ask what disabled people want/need. Non-disabled people are still doing things for us and not with us. Disabled people are the real experts. “Ask us and not our support services”.
* Participants reported not knowing how to go about getting involved with organisations. One participant felt that there are lots of great organisations but that it is hard to know what they offer. She felt that a lot of people with disabilities are isolated and may not hear about things that could drastically improve their lives. The same participant reported that she felt a bit of the imposter syndrome as do some of her friends with disabilities because they don’t need things at the same level as many others seeking support. There was a feeling that most disability organisations are Dublin based and that local ones may not be connected to individual interests and needs. One participant wondered why there were few people with a disability taking a leading role in the community and wondered if there was a feeling of learned helplessness due to being overprotected by family and friends in certain situations.
* Participants discussed how the lack of representation of disabled people in policy/legislation development could be addressed. One suggestions was that organisations including DPOs can try to alert the wider community on opportunities for engagement. Details could be shared, for example, through various fora about the Disability Participation and Consultation Network (DPCN), the Disability Stakeholder Group and local Disability Housing Steering Groups. Also, opportunities to make submissions and consultations coming up with the Government and public bodies could be advertised more widely.
* Participants discussed the meaning of terms like participation, inclusion, equality and disability. They spoke of how they cannot set up a hierarchy of impairment and of the need for cross impairment DPOs to collectively work together. At the same time, some considered it essential to have single disability DPOs, and pointed out that this was a right under the CRPD.
* Participants spoke of the roles of service providers and DPO's and one person who works in a disability organisation that is not a DPO said: “I believe that we all have the same aim of equality for all and that we need to, and can work together in planning and delivering into the future.”
* Participants spoke about how COVID 19 showed what is important in our lives and showed what people can accomplish when they work together towards a common goal with good will. They thought that this might help improve the mentality going forward in government if that attitude was continued.

## Joined up thinking to improve personal supports and public services

* Participants spoke about how joined up thinking is vital to make independent living successful and to ensure that mainstream services learn how to become accessible to all. They thought that the government can sometimes rush through initiatives that need to be better thought through and planned with input from people with disabilities. They suggested the need to consider the needs of disabled people and the elderly more carefully in universal design.
* Participants discussed how legislation is required to mandate co-design on policy and decision making on matter related to disability; that too many decisions continue to be made that negatively impact disabled people; that disabled people are still not consulted or considered in small and big things. For example, one participant mentioned how the local authorities in Capel Street are getting rid of cars but have not even considered allowing blue badge[[2]](#footnote-2) cars to access the area because they don’t consider the needs of disabled people routinely.
* Participants discussed the fact that disabled people in Ireland still do not have a right to assistive technology or a personal assistant service, which increases their independence and facilitates their participation and inclusion. Disabled people are still not able to move around freely because not everywhere is accessible and effective supports are not provided. A question was raised around how can we have real participation and genuine inclusion when we have a resource-based system? This system can mitigate against the rights to family life, inclusive education, employment, sport and leisure and politics.
* Participants spoke of the poverty trap in disability. You have to earn below a certain amount to receive health care like GP or Physio sessions. You cannot save above a certain amount without fear of losing access to these resources. Many people with disability work for free. Many are able to work a certain amount but may not be able to match their social welfare payment without being in pain for days or weeks at a time. Those who give up these resources often fear that their physical ability will not allow them to earn consistently. There is a lot of fear here, which stops more extensive participation in the world of work.
* One participant queried how much real vision there is to address whatever is required to support participation? He queried whether people working in public services and departments are eager to know the real live scenarios? He said: “I contact different departments and they tell me they have to speak to other Ministers in other departments. It takes weeks for them to come back, no matter what, and the more questions you have the longer it takes for them to come back, but even if you have one simple question it takes about six weeks for them to respond. That's my experience”.
* Participants discussed public transport and what was being done to address ongoing unresolved accessibility issues: “Right now train station lifts are broken and it takes a very long time to get them fixed. Sometimes, buses are overcrowded with teenagers so that a person with a wheelchair cannot get on. One suggestion was that perhaps there could be a day for politicians and others working in transport to travel around on the transport systems of Dublin and rural places, to see the situation, to see the things that could be done if there was the will to do so. Actually seeing the reality might make it easier for them to ensure that action is taken and then their work would make a real difference because all lives matter.
* Participants spoke about customer service and customer support. They felt that with things going online there is less and less help available where it is really needed. What can be done regarding customer support, which is bad and deteriorating all the time in many companies and getting worse? There are long waits for help in organisations such as the ESB. Participants felt that the HSE is not well inter-connected within where one section does not talk to another.

## Accessibility and Universal Design

* Participants spoke about how design can be disabling, that it is important for everyone to understand that anyone can acquire a disability at any time as this will help everyone to understand that Universal Design is essential for everyone.
* Participants discussed how authorities can engage in tick box exercises rather than being convinced that they have a duty to make things accessible. Participants spoke about how the authorities can make cursory changes like fitting a ramp for wheelchair users but not looking at the whole process and other supports needed in getting a wheelchair, for example, on to a bus, or around other people that are on the bus.
* Participants thought that more openness within government circles to the concept of universal design in areas such as housing and transport is needed. They felt that openness is improving but there is a need to continue to hammer home the need for universal design.
* Participants spoke about the need for community transport to be accessible, for example, door to door transport could be included in Transport for Ireland initiatives to provide real choice and the free travel pass could be accepted by the schemes which assist in door to door transport.
* Participants spoke of the need to review and update part M of the building regulations because accessible housing and universally designed housing and wheelchair accessible housing is crucial for independent community living. A requirement for UD should be included in the regulations, for example, the percentage of housing in a development that should be UD or UD+ designed, and/or wheelchair liveable.
* There was considerable discussion around understanding UD and wheelchair liveable houses and the misinformation that exists around wheelchair liveable homes. Councils have not listened to people with disabilities and dictate to them about housing, for example, in terms of space which means that the council is essentially dictating to wheelchair users that they are to remain single for the rest of their lives. Disabled people rely on the Irish Wheelchair Association and service providers in more rural areas. There is a need to broadcast the same message around universal design and different levels of Universal Design. This will be key to ensuring access.
* One participant recounted how she looked for accessible rented accommodation online. She use the only filter they had on access which was wheelchair accessible accommodation. She found 33 rental properties in the entire country. She visited each house and 27 out of the 33 houses that said they were wheelchair accessible had steps up to the front door. Of the others, six had no turning circle space. Every single house, bar one, was inaccessible. Contact with a housing search site to request additional accessibility filters was not taken seriously. She said: “In contrast, Airbnb have a fantastic site with something like 20 different filters around accessibility”.
* One participant said: “I am unable to visit parents because of the size and layout of the house so they need to come around instead. Universal Design of homes will address these kind of issues. One can’t just hide behind ‘we didn’t realise things were this bad’ in terms of accessibility and accessible housing.
* In the context of accessible meetings/engagement/communications, a participant pointed out that blind people cannot use the chat function on Zoom and they cannot follow movies that cannot be audio described.

## Conclusion

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

* Real participation from start to finish in all matters that concern persons with disabilities
* Joined up thinking and action within public services and between public services
* Support for the development and work of DPOs
* Accessibility – a vision and a desire on the part of authorities to grasp what accessibility means in terms of disabled people participating in ordinary life – engaging with disabled people to learn what accessibility means in terms of travel, housing etc.
* To improve accessibility, mandate co-design on policy and decision making on matters related to disability
* Universal design needs to be better understood and implemented
* Increase awareness of all that disabled people can achieve like anyone else given the right supports
* For community to exist, there must be inclusive attitudes and actions so that disabled people belong and feel that they belong
* With regards disabled children, parents need positive support and education so that they can consider the perspectives and needs of their child and have high expectations of what their can achieve with the right supports.

# Appendix: Summary of keynote speakers on participation and inclusion

## Dr John Bosco Conoma, Director of the Centre for Deaf Studies, and Assistant Professor, School of Linguistic, Speech and Communication Science, Trinity College, University of Dublin

As the first keynote speaker of the day, Dr John Bosco Conoma addressed common experiences that those who are Deaf can have. Prior to the listening session, participants were sent a link to the 2018 Oscar winning short movie ‘the Silent Child’, which is rich in symbolism and focuses on the family, the deaf child within the family and the barriers to participation and inclusion. (This is a link to view the [Oscar© Winning short British film ‘The Silent Child’](https://www.youtube.com/watch?v=2GbxFIVQv8c&t=4s)).

Dr Conoma considered the movie a powerful and timely reminder that people are still not being heard and that thousands of deaf children and adults today are having the same experience of exclusion and isolation as portrayed in the movie. He identified points illustrated artistically in the film as common experience in terms of participation and inclusion from the family unit outwards and the learning from them. The points and the learning from them included the following:

* **Attitudes and understanding the lived experience:** Children struggle because the family expect them to fit into their world but they don’t try to fit into the child's world. **Learning:** The family can meet the child – even halfway – in trying to understand his/her perspective and world.
* **The dinner table syndrome:** is a collective experience rather than a medical term and it really exists out there. The deaf child sits there excluded. **Learning:** The family need to first become aware of the child’s need to be included and find ways to do that.
* **The capacity to speak and to listen:** The capacity to speak and listen was demanded of the child. Parents can dismiss the experience of professionals and cling to the hope that a child will begin to speak and communicate in school without sign and without support. **Learning:** Rather than seeing all from one’s own viewpoint try to see what is realistic from the perspective of the child and listen to the professionals advocating on the child’s behalf for the benefit of, for example, using sign language etc.
* **Signing was seen as a stigma:** Parents can be overwhelmed with their own disappointment that the child doesn’t speak and doesn’t qualify for a cochlear implant, etc.They may feel a failure themselves in not relating well with the child.They can continue to cling to wish that they child will become ‘normal’**. Learning:** Parents need help to overcome their issues and feelings so that they can advocate wisely for their child.
* **Low expectations:** Low expectations are common and families are surprised to see progress as they do not expect it. They are often dismissive of the child’s future possibilities. **Learning:** Parents need education and training to understand that the child can be the highest of achievers once the right supports are accessed.
* **Eye contact and communication:** There can be poor eye contact with a deaf child where one does not know what to do and how to communicate. **Learning:** Eye contact is incredibly important for deaf people because it's getting sight of a person's emotions and dialogue. Families and formal educators need to know this.
* **Contact with other deaf people:** Children can be transformed when they meet other people like them. **Learning:** Deaf children need to meet other people like them including adults so that they realise they are not the only one, and that they too can have a purpose in living just as other d/Deaf people have. Role models who are deaf is important.
* **Language acquisition, verbal or signed:** Parents can miss out on important opportunities to engage with their own child and help him/her to flourish. Parents can struggle with that idea that they can use all the options open to them and that they don’t have to choose between one and the other. For example, they can fear that if the child learns sign language, he/she will never try to speak. **Learning:** For every child, whether deaf or hearing, disabled or not, the perfect time for verbal or signed language acquisition is from birth to the age of five. Sign language can be made verbal and visual – making reference to books, showing it in the context one is in. Using the visual to describe, showing sight and showing it in real life is a key teaching method.
* Discussion included what role various people play in improving the situation. While there may be policy and legislation in place, there are still expectations to manage in relation to deaf children. Health professionals attend to the auditory aspect of deafness while the family and social aspects are best left to experts in these areas. The social and deaf cultural side of things is important so it is important that deaf children experience deaf culture and meet not only people who have experience and sign language skills but people who are deaf. It is crucial to have role models as a visual path for the future. In deaf schools where they are more deaf adults working, they are role models for deaf children, who realise they too can be teachers, staff in schools, etc. They too can fulfil their dreams – how important!

## Nicole Norton and Orla and Brendan O'Reilly

Nicole and Orla and Brendan spoke about their lived experience of community and independent living and then showed their respective videos developed as part of Inclusion Ireland’s 19 stories about inclusion.[[3]](#footnote-3) These videos have been widely watched and have proved very useful for people to understand the lived experience of persons with disabilities.

Nicole has worked as a counsellor and play therapist assistant with children, preteens and adults for seven years in a charity that works with children and teenagers with special needs, including Cerebral Palsy, Down’s syndrome and Autism and many more disabilities. Her work includes one-on-one counselling with parents and group work with children, including play therapy, administrative work in the office and also participation in fundraising. Nicole loves her work and enjoys the various aspects of her work and gets a lot out of it. Nicole’s message is to live life to the full, be pro-active, fight for your dreams, overcome negative attitudes, and listen to those who are positive and encourage you and stretch yourself to develop your talents. Nicole said that, unfortunately, to this day too many people will still see the disability first and they may not even see your mentality and personality and so “even though I am well able, they see the disability and not what I can do and am capable of.” Nicole considers it important in spite of such negative attitudes to keep one’s own focus on the positive, to be determined to overcome the obstacles, to smile and to keep going, and to enjoy every day life, and being with other people, and having friends, in spite of the setbacks and ups and downs that are part of life. When asked about her biggest challenge she identified it as overcoming her fear of not being able to work and give parents and children the support they need. The second biggest challenge is to try and get people to look past the disability and see who you are, your personality, what you are, and your mentality.

Orla and Brendan spoke about their experience and about the obstacles they had to overcome to attain their goals. Some people didn’t think they should marry or would be able to live independently. However, they are happily married, live independently and have a good life. They got their own home after a lot of struggles but kept going with support from their respective families who encouraged them to follow their own vision. They spoke of their first landlord who would come and ask them if they had permission to live independently as they were people with extra support needs. She seemed to be afraid of being held responsible if something went wrong. She would come to their house when they weren’t there, to make sure everything was okay. They didn’t like this invasion of their privacy without being asked and so found another place. Finally, after 13 and a half years they got their own place.

Brendan has had a steady job for more than 14 years. Recently he passed a barista course. He wants his job to push him further and to improve his skills in an ongoing way. Both of them give a couple of talks to students in Trinity every year and also have gone to talk at different colleges in Ireland. While they used to go to a day service they changed to a service for people with less support needs.

We wanted a service where we could go in and meet up with a key worker if we needed to have key working time, or if we needed to get involved in the community, and they would give us information about it and we'd just check up on it. The service helped us to get independent skills. We learned how to make a shopping list and not to spend over what we had.”

During lockdown they were more dependent on their support service - mainly for company.

Staff would come down when they were free and go for a walk on the beach with us because we live beside the coast and that company really got us through lockdown. Sometimes, they would come back to our house and do some cooking with us. We were also doing Zoom meetings, singing with our service and doing bingo and other stuff that kept us occupied. The support service also helped us get our place and they have helped many others with housing.

When asked about their biggest challenges, Brendan and Orla mentioned several including, for example, overcoming the fears of moving out of home, of having the confidence and skills to move out and manage bills and the home:

I never thought I would do it and it is the best thing ever, although it is expensive to live on your own but we are careful and we always manage. We put some money away for holidays and stuff, so we are actually hopefully going to go to Portugal in September this year.”

Another challenge they faced was whether the support they needed would be available if they needed it.

In response to questions about whether they had made many friends in the community and, if so, where are good places for making friends, they gave varied perspectives. They keep to themselves a good bit because of the negative attitudes they encounter although they have some neighbours who are good to them. For example, if they go away, a neighbour down the road will mind their little cat. Brendan makes friends by walking in the park with his dogs and because he loves dogs. His favourite place to walk is the beach. He also knows people as he is originally from a neighbouring area. However, overall, he prefers to talk to people that have a disability.

It's just my experience, I feel around people that don't have extra support needs that they don’t understand me. Maybe that's just me, but that's the way I feel sometimes. I just find it hard to talk to people that haven't got extra support needs.”

In addition to playing football for the local club, he plays social basketball and the group fundraised for the Ukraine with a basketball Marathon, and raised 1,925 euro. He also plays basketball with Special Olympics.

When asked what anything they would like to see in place around them that would make it easier to make more friends or meet up with people that you wanted to meet up with, Orla thought it would be if there was a little local club where they could mingle with nondisabled people “so that they would get to know about our lives and what they are like and what we go through.”

## Fiona Weldon, Independent Living Movement Ireland (ILMI)

**Fiona** has 30 years of experience in working in the Disability Sector. All of her work is motivated by the reality of the effects of segregation, exclusion and non-disabled professionalism. Fiona promotes the need for a Rights Based Model of Support to people that are labelled disabled that is driven by the Social Model of Disability and the Philosophy of Independent Living as professed by the Disabled People’s Movement. Fiona works for a Disabled Peoples’ Organisation (DPO), Independent Living Movement Ireland (ILMI), “which means that most of the people that work here are disabled people, and other people that are on our side”.

Some of the points made by Fiona included the following:

* The ILMI deeply value the importance of the lived experience of disablement and this is reflected in all of its work. The ILMI believe that there is a real need for autonomous, collective spaces for disabled people to make real change. DPOs are about creating collective spaces and strategies and to make changes to the systems that do not work for us. “It is really important to us that we campaign and use strategies collectively to bring about change”.
* Participation is the action of taking part in something. It's about being active and it needs to mean something. There is a value in doing it. Inclusion is the act of including. It is about being included. It is about the practice of including and accommodating people who have been historically excluded. Disabled people were, and still are to a large extent, considered by society as not normal. The result is that disabled people are de-valued, left out of the ordinary rhythms of daily living, and many are still segregated. Some have attended special schools, or are in special classrooms, or are leaving the classroom to receive extra support. Some go to special day centres and some are expected to go to specialised day bound recreational activities and some live in specialised accommodation. What is really important here is that these special schools, day centres, recreational services, activities and accommodation pavilions are for non-disabled people but are mostly run by non-disabled people.
* Participation and inclusion have to be genuine, real and authentic. The UNCRPD states that that disabled people must be involved in drafting all policies and laws that affect our lives. This means that disabled people need to be sitting at the table and not just disabled person but many disabled persons. It's about collective action. Disabled people need to be included in society, to feel part of and be part of the community, participate in family living, have access to inclusive education and real employment and participate in ordinary sport and leisure and to be active in politics and live in an accessible environment. Article 4.3 of the UNCRPD makes specific reference to the role of DPOs and the need for their collective voice. Fiona asks how this can be done in a resource-based system with no right to assistive technology or a personal assistant service that can increase their independence.
* Non-disabled people are still doing things for disabled people rather than with disabled people. Lived experience is essential as we have seen today with the speakers. They have all spoken about living ordinary life. They are the real experts. DPOs are essential. Disabled people and DPOS know what works and what doesn't work and they and not their services need to be asked.
* Anyone can acquire an impairment at any stage of their life, so it is in the best interests, as a society, that everybody participates and is genuinely included. Everyone wants the same thing - to live good, ordinary lives.
* The disability inclusion strategy is about participation, choice, control and feeling equal, it's about being able to participate in choosing where to live, what to do during the day, who to live with and who provides support if support is needed.
* Universal design is about designing for everybody. Universal design is the design of products and environments to be usable by all people without a need for adaption or special design. This means our environment, housing, transport system, how we use information, how we read it and how we use technologies and products. Universal Design is for everybody and just not disabled people.
* “Disabled people are all intersectional - men, women, lovers, brothers, sisters, employees, colleagues, friends, but also survivors of inequality, of the individual model of disability that is steeped in our system of support. Disabled people are survivors of devaluation, of oppression, segregation and institutionalisation.”

To conclude her presentation, Fiona Weldon, showed a video entitled, ‘We, the 15’ <https://www.youtube.com/watch?v=gHCDvdCaJhI>)

1. https://nda.ie/publications/others/research-publications/lockdowns-unlock-innovations-report.html#:~:text=The%20widespread%20and%20unprecedented%20disruption,that%20impacted%20persons%20with%20disabilities. [↑](#footnote-ref-1)
2. Blue Badge holders are entitled to park in accessible parking spaces. [↑](#footnote-ref-2)
3. This is a link to the 19 stories on the NDA website <https://nda.ie/Policy-and-research/Research/Research-Promotion-Scheme/19-Stories-of-Social-Inclusion-%E2%80%93-Ireland-Stories-of-Belonging-Contributing-and-Connecting1.html> [↑](#footnote-ref-3)