

Summary of the Consultation, ‘Building back better post COVID-19’, held on 14th May 2021

June 2021



**Údarás Náisiúnta Míchumais
National Disability Authority**

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Introduction

The full participation and inclusion of persons with disabilities in society is a core ambition of the United Nations Convention on the Rights of Persons with Disabilities (CRPD). As part of achieving this goal, the CRPD also mandates that States put structures in place that engage persons with disabilities and their representative organizations, i.e. Disabled Persons Organizations (DPOs)¹ in the development of policy and legislation (Article 4.3), and in the implementation and monitoring of the Convention itself (Article 33.3).

On 14th May 2021, the National Disability Authority (NDA) hosted a virtual event to hear directly from persons with disabilities and their representative organisations on the theme of 'Building Back Better Post COVID-19'. The aim of the event was to hear perspectives on the impact of the pandemic on education, employment and daily living and to hear about innovations and developments that could be adopted in the post-pandemic world, including the use of technology in these fields, in order to achieve better outcomes for persons with disabilities. The learning from the event will inform NDA advice and information to the Minister, department officials and the wider public sector. The event was also an opportunity for persons with disabilities and DPOs to hear from each other. While the NDA has always consulted with persons with disabilities, the 'Building Back Better Post COVID-19' consultation was the first in what the NDA hopes will become an annual 'listening event'. This event will not replace the ongoing collaborative and consultative participation of persons with disabilities on specific items in the NDA's work programme, through advisory groups, focus groups on specific themes and other surveys and consultations

Sixty-seven participants attended. The first part of the event featured keynote speakers who have lived experience of disability:

- James Casey from the DPO, Independent Living Movement of Ireland (ILMI);
- Adam Harris, CEO of the DPO, AslAm, Ireland's national autism charity
- Catherine Kelly and Leia Donnelly from the Walkinstown Association for People with an Intellectual Disability (WALK).

¹ The CRPD emphasises that for an organisation to qualify as a DPO, it must be (largely) an organisation **of** persons with a disability and that a **majority** of persons with disabilities should form the management, staff, members, user groups, volunteers, etc. DPOs approach issues from a rights based perspective and use the Social Model to proof everything they do. Some DPOs work across impairments.

Questions and Answers followed each presentation. This was followed by six breakout sessions to further discuss the consultation themes. The event concluded with a participant synthesising the experiences and suggestions expressed in each of the break out rooms so that the entire group could have a sense of the topics discussed and points raised.

This report summarises the discussions and inputs during the three hour consultation. It is largely comprised of paraphrasing and occasional direct quotes to reflect the voices of persons with disabilities expressed on the day. The language used reflects a combination of that used by some participants (disabled people) and that used as standard by the NDA (persons with a disability).

This report will be presented to Anne Rabbitte, Minister of State with responsibility for disability and to officials in the Department of Children, Equality, Disability, Integration and Youth. It will also be published to the NDA website.

Summary of discussion

The consultation focused on harnessing learning regarding positive ways to build back better in education, employment and everyday living, following the COVID-19 pandemic. It emerged during the discussion that many participants had experienced positive developments in their lives during COVID-19 and expressed their hope that the positive innovations and gains achieved during the pandemic would not be lost but, rather, would be built on for the longer term. They hoped that learnings from more negative experiences during the pandemic would lead to mechanisms being put in place to prevent such actions being repeated in future situations of crisis.

Adam Harris, quoted the poet Robert Frost who said that “the best way out is always through”. He noted that while the pandemic brought challenges that already existed to the surface and created some new ones, it has also presented us with the opportunity to build back more inclusively:

There is an opportunity to build back better because everything we took for granted about education, work, the health system, communities just over a year ago is now in question. Things we might have suggested a year ago that would have sounded crazy, are now things we have all been doing, and have had no choice but to do them, and the sky hasn't fallen in on us. There is the opportunity to ask how we can create communities that are much more inclusive, much more accepting and much more empowering for

people within the context of disability. (Adam Harris, keynote speaker)

The remainder of this report summarises the views of persons with disabilities as voiced in the consultation. These views are grouped into the categories of representation and voice, universal design (UD), technology and education and employment.

Representation and voice

The importance of improving representation/participation in line with the CRPD so that disabled voices are at the centre of discussions was raised throughout the consultation event:

Parity of voices is important and disabled persons should have the opportunity to be present when disability issues are discussed and addressed. (Consultation participant)

Participants stressed the importance of members of the government and other bodies hearing directly from persons with disabilities and getting their perspectives on possible solutions to disability issues. They pointed out that the pandemic has highlighted the work that still needs to be done so that persons with disabilities are listened to regarding disability issues. One participant gave the example of the discussions and disagreements regarding the re-opening of schools for children with disabilities after Christmas 2020. While there were many stakeholder groups involved voices of disabled students were not at the table:

That is not in line with the CRPD nor does it live up to the adage of 'nothing about us without us'. We need to make sure that when we are talking about disability issues, the voices of disabled persons are front and centre. (Consultation participant)

Participants made positive references to Minister Anne Rabbitte, Minister Roderic O' Gorman and many others who have engaged with Disabled Persons Organisations (DPOs) and are eager to hear the lived perspective of persons with disabilities. Referring to the spend on disability services, participants stressed that more listening and learning from persons with disabilities can help to identify solutions that result in more efficient and effective use of resources. A participant made the point that the complexity in peoples' lives, including the lives of persons with disabilities, makes it imperative to listen:

Understanding complexity and that everyone is an individual underlines the importance of talking to people rather than making

assumptions, and taking the individual person into account...
Persons' needs are different. (Consultation participant)

Participants acknowledged that while service providers, charities and other agencies and statutory bodies do great work, they cannot represent persons with disabilities nor should they be able to impose decisions on persons with disabilities without involving them in the decision-making processes. One of the keynote speakers articulated his perspective on the matter:

A service provider of large charity speaking for me is like having Ryanair talk about passenger's rights. Men describing women's lived experiences or white people describing black people's lived experience is as futile as non-disabled persons describing disabled person's lived experiences. We wouldn't ask men about women's rights issues. We wouldn't ask heterosexual people about LGBTQIA+ issues. But somehow, it is deemed acceptable to ask non-disabled people about the issues that disabled persons face. With true representation, you gain an authentic sense of the issues that are affecting disabled persons, which makes it more likely that you will find a solution to them. (James Casey, keynote speaker)

One participant felt that some services could seem to “force” persons with disabilities into dependent situations and hoped that this would change. At the same time, this participant noted that

...while disabled persons are the experts, and must represent themselves, one should also consult persons without disabilities as some are great advocates on disability issues. (Consultation participant)

Participants' spoke of the importance of further transitioning towards rights based models where a societal view of persons with disabilities as having rights and their own voice is taken seriously. One participant pointed out that issues that have affected many people throughout the world during the pandemic are issues that persons with disabilities have struggled with in an ongoing way for decades. The suggestion was made that if the non-disabled world reflected on their experiences of the last months, they might get a glimpse of what persons with disabilities have had to endure. They have been told where they can go, what they can eat, what they can do, whether or not they can work from home, participate in this or that event or activity, etc.

Catherine Kelly and Leia Donnelly spoke of the challenges faced when the pandemic struck and persons with intellectual disability living in their own homes, but attached to a service provider, fell under a HIQA framework. Leia described

her experiences in detail. Catherine described how nursing home guidelines were enforced which restricted visiting and their ability to go out and about. They felt that this blanket application was unfair and had a detrimental impact on people's mental health, and that no one had considered the legislation regarding capacity, decision making and informed consent before the restrictions were applied. This infringement of the rights of disabled persons is an example of how disabled persons are not respected. To build back better, person's rights must be respected and their voice must be at the centre. Catherine balances their argument by acknowledging that in a pandemic one needs to

...recognise the importance of the infection control measures that were put in place and the reasons behind the decisions that were made. However, crudely applying nursing home standards and restrictions on people who didn't live in a nursing home but lived either on their own or in shared accommodation with a maximum of three other people without any consultation was in direct contrast to nothing about us without us' (Catherine Kelly, keynote speaker).

Participants spoke throughout the event about the use of language. There was a strong feeling that in charitable and medical models, language can be used in ways that negatively affect the perceptions of persons with disabilities. Participants therefore called for the emphasis to be on using the language of the social model when discussing disability matters. Some participants felt that a lot of policies are still rooted in charitable and medical models and are patronising. The way that has been clearly identified in the CRPD to get out of this is to have persons with disabilities at the table:

Attitudes, representation, and equality must be changed and equality is enforced through rights. Rights activism can be a very simple thing. It can be as simple as writing a letter. Disability equality training is important and is distinct from disability awareness training and one should not think they are the same. Technology too can play a crucial part in allowing people to come together (James Casey, keynote speaker).

Participants indicated that they found the consultation to be a good opportunity to engage with other persons with disabilities, learn about Disabled Persons Organisations (DPOs) and hear new perspectives. The need to strengthen collaboration among persons with disabilities was raised. The need for increased awareness of what they have in common with each other and the importance of the collective as well as individual efforts to attain societal participation and inclusion was also raised. Participants spoke of the need for persons with disabilities to come together, informally and formally, to learn from each other such as through film clubs, disability-only spaces, local active peer support groups,

etc. There were descriptions of positive experiences of more online networking during the pandemic. Participants spoke about hoping to build on and expand this collaboration through DPOs and other disability networks and to increase online as well as face-to-face networking and friendships, including across disability types. A participant spoke of the success of the civil rights movement where people talked about and sought solidarity - living together, eating together, going to school together, getting used to being together and acting together to attain their rights and drew parallels with striving for disability rights.

Participants spoke of their feeling that implementing the CRPD and promoting the formation, funding and strengthening of DPOs as recommended by the CRPD, was essential in accelerating the transition to a social and human rights model of disability. They discussed how participation of DPOs in local and national structures can improve representation and give public structures access to the authentic and diverse voices of persons with disabilities. One participant explained how DPOs can represent persons with disabilities regardless of the disability type:

What I can understand well is a shared experience of prejudice and a shared sense of challenges and the various ways of addressing challenges. DPOs are only as good as their members. They are a conduit for their members to engage in meaningful change. (James Casey, keynote speaker)

Universal Design (UD)

The participants discussed how Universal Design is essential for the inclusion and participation of persons with disabilities. It facilitates independence for all, as the “accommodations” made for persons with disabilities benefit others at different moments and stages of their lives, e.g. parents negotiating physical spaces with prams, other small children and shopping; older persons with limited mobility; students on crutches etc. will all benefit from UD. A basic Universal Design principle is to inform its design with user experience and the perspectives of persons with disabilities. One participant expressed their opinion that UD is the best way to implement the social model of disability:

...if products, services and supports are not built according to UD, they impose dependence on disabled people. Independence is good for disabled people because it allows them to participate and contribute to their communities and this is good for everyone.
(Consultation participant)

Participants discussed some of their experiences of issues relevant to UD during the pandemic. One participant spoke about how the design of school buildings,

particularly large second level schools, can be overwhelming for some students, for example, students with autism. For many autistic children, the day-to-day experience of going to school may not feel like a safe experience but rather an overwhelmingly stressful one to such an extent that they can't learn. If continued, adjustments made during the pandemic to reduce class size and introduce social distancing that include more spacious, structured environments, which are more sensory friendly could have ongoing benefits to students with sensory issues. Participants emphasised that inclusion is not only about a person being permitted to enter a building, but is about creating environments where people feel accepted and are able to learn and thrive. It was also noted that during the pandemic the education world became more visual, which was helpful for students who learn in a more visual way, and there are opportunities to build on this in the future.

Participants also discussed the need for a UD approach to managing aspects of the pandemic response, including vaccination centres, suggesting that it would be useful if more consideration could be given to their location relative to the location of public transport and accessibility of the building. It was noted that it can be difficult for many people with disabilities who live far from a vaccination centre to get there. One participant gave an example of a visually impaired person who travelled to a vaccination centre by bus and had to cross a four lane dual carriageway, navigate his way to the stadium that hosted the vaccination centre and, then, within the stadium itself. One participant gave an example of going to a vaccination centre where she encountered difficulties with lip-reading due to the masks worn. She suggested that if the centre had provided written information she would have had a more positive experience. While the HSE and the Department of Health have been praised for using Irish Sign Language (ISL) interpreters in their press briefings, some participants criticised the HSE for having limited or no provisions in place for persons with a hearing impairment in the day-to-day pandemic response activities. For example, the system for contact tracing is telephone-based.

Participants discussed extensively how street accessibility can be compromised by changes made in response to the pandemic, including the expansion of outdoor dining. They felt that it will be important for this development to be well managed by the local councils to maintain accessibility for all. Wheelchair users, older people, people with visual impairment, people pushing prams, etc. need access and space to navigate streets. Outdoor dining should be accessible to wheelchair users by providing the extra space needed, as well as accessible toilets. Participants called for all those involved to take account of the lived experience of disabled persons in the delivery of their roles. For example, a person with a visual impairment may experience difficulties in maintaining a two meter distance from others as they cannot see markings on the ground. They

may experience difficulties in locating hand sanitiser when they enter a building. It was suggested that if there was greater general disability awareness, others would be more likely to notice a blind or vision-impaired person and give them the required two meters' distance wherever possible and offer verbal instructions where relevant. For example, they could tell a blind person that the hand sanitiser is mounted on the wall to the person's left and at eye level, etc. Many blind and vision-impaired people welcome assistance as long as others announce themselves first, offer help and wait until their offer is accepted.

Some participants stressed the need for more education and training in UD, particularly in courses such as Architecture and Design, and for staff working in areas such as urban planning, local authorities and councils, transport, etc. They spoke of experiences in education and professional work where the whole issue of UD and accommodating the needs of persons with disabilities seemed to come as an afterthought or an add-on.

One participant spoke of how, during the lockdown, some families found it difficult, particularly in small homes, to accommodate offices, schools, play areas and canteens at the same time. For a person with sensory issues, trying to learn in this environment can be an extreme challenge. Examples were given of imaginative ways in which people had redesigned their homes to accommodate education and work, such as pop-up tents to create sensory spaces for children with autism, and developing methods of communication between people sharing the space to negotiate time alone for example. One participant spoke about his understanding of the Housing Adaptation Grant and how it could be applied for and used to install an additional room. He said that such a room could be used as a sensory room where indicated. Such supports in the home can make a big difference for families.²

Participants' spoke of their hopes that Universal Design will be more widely adopted in the housing sector to facilitate adaptable homes to accommodate their changing needs, including allowing them to be able to age at home.

Technology

The pandemic saw a dramatic and rapid increase in the use of technology to conduct education, work and social interactions virtually. Participants agreed that this has had many positive impacts for persons with disabilities. For example, it has allowed many persons on the autism spectrum and other persons with

² <https://annerabbitte.ie/housing-adaptation-grants-can-be-used-for-sensory-rooms-minister-rabbitte/>

disabilities to feel more comfortable in their working lives due to not having to commute or being more in control of the sensory environment at home.

Participants advised that attention to ensuring technology is accessible is vital going forward and that the provision of adapted digital literacy support in education is crucial. If not, there is a risk that the expanded use of technology and doing things remotely will become another barrier to participation. There was some discussion on the need for some apps to be adapted to accommodate people with visual impairments and learning disabilities. There was a suggestion that grants for training and IT equipment for disabled individuals need to be rolled out and updated every couple of years. Participants suggested that technical supports, for example, those provided through reasonable accommodation grants for employment or through the education system, be provided to individuals rather than to educational institutions or employers. Participants felt that this would allow the technology to accompany the person as they move through the education system or change employment.

With the move to flexible and blended working, participants recognised that there may also be a need to provide two pieces of equipment - one for the office at home and another for the onsite office - and that this may need to be provided for in any reasonable accommodation fund.

Participants also raised the issue of the grant structure for aids and appliances and felt these could be usefully reviewed and reformed with the aim of applying a social rather than a medical model. The purpose of the aids and appliances scheme should be to promote independence and to incorporate all the relevant software and technologies for that. Participants felt that if the grant scheme was managed outside the HSE, this could help to distance it from the medical model. Such a move could give choice in that someone would be able to purchase aids and appliances that suit them and to get the best value for money.

One participant spoke of the sense of control that technology gave her over how she managed her environment:

When I was operating from home, I became very confident. I felt a wave of safety because outside people can be very patronising. Tech gave me a louder voice and as people didn't see a disability, they heard and listened to my voice. (Consultation participant)

Another participant said that she only became aware of disability activism when everything moved online. One of the keynote speakers spoke of how the DPO they were a member of has reached many more people during the pandemic than they had ever previously done, by making resources available online:

Some of the family support training events we have provided would have been held in hotels around the country. There were always a large percentage of families who, because of their circumstances, couldn't get out to attend such support events. Now that we are providing support virtually into people's homes for the first time, there has been a massive increase in engagement. As a DPO, we have learned new ways to engage with our community and we want to build on these. (Adam Harris, keynote speaker)

For those with mobility issues, the use of technology can help to mitigate challenges such as inaccessible transport, the lack of PA services and the difficulties of bringing people together from a large geographical area. As one participant said:

Ireland tends to be Dublin centric, so unless you live on one of the main train lines, it is not easy to get to Dublin with a mobility impairment. The use of technology facilitates wider participation with the consequent emergence of a more authentic voice with more diverse perspectives. (James Casey, keynote speaker)

James Casey, a keynote speaker, spoke briefly of a social inclusion cross border project, which supports persons with disabilities from 16 years of age to create community connections locally and online. When the first lockdown was imposed, it delivered training virtually. Its purpose is to support choice and independence and help disabled people to access mainstream lifestyle choices rather than traditional disability-service provider 'care' options. Participants saw value in such programmes and would like to see more of them

Education and employment

The areas of education and employment were particularly impacted by the COVID-19 pandemic. Participants spoke about the need to ensure that services for persons with disabilities in education and employment, as well as in healthcare and the community, are categorised as vital to ensure that negative impacts could be managed in so far as possible. It was noted that in the current education system, non-statutory supports are subject to availability of resources, with a feeling that this approach has not worked and the rights of students have not always been upheld. Participants felt that as a result, there is a need to push for a rights based approach in the education sector and also there is a need to clearly inform policy makers how the current system does not work.

Participants felt that a deep reform is needed to arrive at an inclusive education system. One suggestion was to examine the statute books and relevant pieces of legislation and amend them as necessary. The decision to re-examine the

Disability Act 2005 and the decision by the Minister for Special Education to commence a review of the EPSEN Act 2004 were seen as positive developments. Participants discussed how rights based legislation can ensure that essential supports put in place are ring-fenced, including in a mainstream context and cannot be diverted elsewhere. In addition, one participant suggested that a disability proofed education emergency plan is needed to ensure continuity of provision for children with additional needs in the case of future major events like the pandemic.

While persons with disabilities have moved into mainstream education in large numbers, participants felt that the mainstream education system has not yet changed sufficiently. One area that participants considered had not changed enough is the examination system, where the Leaving Certificate System is currently considered the main measure of success. However, due to the pandemic, an alternative form of assessment for the Leaving Certificate has now been used in two successive years, providing evidence that it is possible to create different methods of assessment that are more inclusive of all persons with disabilities and all methodologies of learning. One participant spoke of her happiness in being able to be assessed with predictive grades instead of the Leaving Cert and thought that continuing such an alternative system would be a good thing. Other participants hoped that the greater access to digital learning resources in university education during the pandemic and the increased digital skills learned can be maintained and expanded.

Some participants described experiences of how, during home schooling, children with visual impairments were given technology that was not accessible and they were expected to access apps that were not accessible. There was a similar story with a participant in Higher Education who spoke of inaccessible technology such as laptops with screens that are too small. A particular challenge for children with visual impairment is that routes in schools changed to facilitate social distancing and so they needed support when returning to school. In addition, it was described how supports for children with visual impairments are currently linked to the academic year and therefore not available in the summer. One suggestion was that a tailored approach with a visiting teacher-model could be made available through the summer provision programme.

An example was given of thirty-five students in a special school who did QQI education on-line and had a positive experience, illustrating that a greater use of technology in education can greatly improve accessibility for some.

Most participants thought that where possible, the option of working and studying from home should be continued for everyone post-COVID-19. They thought it would be good to retain and make use of the advances that have been

developed in remote learning, as well as introducing flexibility and choice around whether one accesses education and work remotely or not. It was recognised that new ways of working can be good for some but not for others, so having choice is important:

New ways of working should be made available for disabled and non-disabled alike. If non-disabled persons can adopt new ways of working then disabled persons can feel more comfortable choosing the ways of working that suit them best. (Consultation participant)

Participants wondered how best to capture, discuss and incorporate learning and positive practices in work and education from COVID-19 and “have it acted upon by government”.

One participant spoke of being required to stop working with the lockdown while all the other staff in the office were redeployed to other jobs. She felt that perhaps she did not get the choice like the others because she has an intellectual disability. Participants also spoke about paid employment and the difference between training and a job/work. They felt that there can be many placement and volunteering opportunities but very little access to paid employment. There was a suggestion regarding a need to formalise the structure – a National Standard perhaps - for trial employment/ apprenticeship for those with an intellectual disability or any other disability, but that persons with disabilities would need to be at the table when setting any such standards. The disparity in employment rights and pay of persons with disabilities in sheltered work compared to public/private sector employment was noted.

One participant spoke about the length of time it takes to receive a reasonable accommodation for employment:

The time taken for reasonable accommodation grants to be approved needs to be shortened (the wait may be 12-18 months), so even if you are qualified you are unlikely to get the job and it is very disconcerting going into interviews knowing this. (Consultation participant)

Participants thought that community groups rather than service providers may be better placed to tackle training and employment for younger people as they can facilitate persons with disabilities having more contact and interaction with others in the community. Participants spoke of the lack of progress with regards to provision of Personal Assistants (PA) and discussed how a good PA system should cover social care, educational, employment and personal need. Lifelong independent living may require access to supports ‘from cradle to grave’.

Conclusion

Participants considered that while the pandemic was challenging in many respects, it has offered a view of how society could be more inclusive of persons with disabilities. Building back better will be dependent on policy makers listening to and learning from persons with disabilities. It will also require a move away from the medical model of disability and embracing a social model. While this is being done to some extent in relation to universal design and technology there is still scope for improvement in many sectors.

Participants expressed hope that the learning and gains made during the pandemic will be consciously retained and built on and not lost in the drive to recover.

The pandemic brought into focus challenges that already existed but lay hidden below the surface. It highlighted ways of doing things that facilitate participation so building back better is a must – it is addressing what was amiss in the first place and then going further. (Consultation participant)