Creating our Future 2021:

Ideas from the National Disability Authority's "Big Think" Brainstorming Event

November 2021
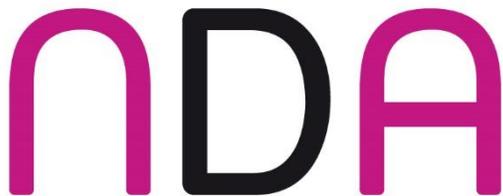
Údarás Náisiúnta Míchumais
National Disability Authority

Introduction

On November 23rd 2021, the National Disability Authority (NDA) hosted a brainstorming event for the Government's 'Creating our Future' project. 'Creating Our Future' is a chance for everyone in Ireland to tell the government their research ideas to help make our country better for everyone. The NDA invited people with disabilities to this event as a way to make sure that their views would be included in this national project. The event materials were made available to participants in Easy to Read format and in Large Print. Irish Sign Language interpretation and real-time captioning were provided at the event. This document reflects the ideas raised during the event, and the NDA is submitting it directly to the Creating Our Future project team as a record of same.

Although over 60 people registered for the event, only 16 people attended the virtual brainstorming session. These were a mix of representatives of disabled persons organisations, other disability organisations, individuals with disabilities and people supporting others to participate. A list of participants is available in Appendix A. The brainstorming sessions took place in small groups, and notes were taken during these sessions. After the event, these notes were summarised and rewritten as research questions or ideas for the purposes of the Creating our Future project. Because of this, the full depth of the discussions is not fully captured, but the NDA have made every effort to include all points raised, and they are presented below under thematic headings.

Two organisations, Voice of Vision Impairment Ireland and Independent Living Movement Ireland submitted their research ideas via email. These were merged with the ideas gathered at the brainstorming event, but they can also be viewed separately in Appendices B and C.

The NDA was delighted to gather 101 ideas for the Creating our Future project. This document records these ideas and is being submitted to the Creating our Future team. The ideas gathered cover many aspects of the lives of people with disabilities, but a strong message underpinning many of the discussions was the need to consult with disabled people and move to co-research designs, where people with disabilities are partners in the research, as well as the need for regular evaluation of the service experiences and outcomes for customers with disabilities, in both public and private sectors.

101 research ideas for Creating our Future

Human rights and disability

1. What is disability and what is disability inclusion?

2. What do human and civil rights mean in English? How do we reinforce them in terms of access to them in everyday life?

3. Why is government allowed to remove vital disability supports like travel allowance even after we signed the UNCRPD?

4. Place people with disabilities at the centre of feedback around implementation of UNCRPD. They are the experts on how it should be implemented.

Consultation with persons with disabilities

5. How much consultation with people with disabilities is proportionally representative of the range of disabilities people experience? Are organisations that represent people with visually obvious physical disabilities favoured in consultation?

6. How can the Public Participation Network (PPN) structures be strengthened and used for consultation and participation? There were mixed views on whether PPNs work.

7. Who is listened to by local and national government about disability, and are people with invisible disabilities sufficiently included in consultation?

8. How can we make disability consultation effective and inclusive at a national level and not just a tick box exercise by consulting with some of the big charities?

9. Research is required to gather people's perspectives on 'real engagement'. Engagement with people with disabilities by local authorities etc., is often seen as tokenistic (e.g. inclusion of one person with a disability in a group is seen as engagement).

10. Research is required to measure how engagement is used and what makes it 'meaningful'. Measure the impact the voice of people with disabilities is having – look at the outcomes of engagement.

11. How can engagement between high government and people with disabilities be facilitated?

12. Make sure to engage in consultation with the deaf community.

13. How do you get the voice of people with disabilities to be united so they speak with one voice rather than the fractured approach that currently exists?

Inclusive research and research dissemination

14. Research on inclusive research and on educating the wider public about research and how they might participate.

15. More of a focus on co-research, working together with people with disabilities.

16. Inclusion of the deaf community in research –e.g., in evaluating the implementation of a service which impacts the deaf community.

17. All research needs to involve its main stakeholders. Disabled people need to shape research questions and methodologies. Value the lived experience.

18. Disabled people need avenues to request research that is purposeful.

19. Dissemination of research needs to be widened and made more accessible. Disabled people need to be able to read/understand its purpose and content, for example more use of Plain English/easy read/short video could support wider readership. Presenting findings to disabled people would also be useful.

20. Research about us should embrace the social model of disability with a view of empowering disabled people and not perpetuating difference. The use of medical model language needs to stop.

Implementation and utility of research/policy/guidance

21. Why does the government not implement all the good reports on what needs to happen? There is a lot of good research and advice, why are they not implemented?

22. How to ensure research about disabled people informs both policy and practice in a meaningful way? Currently this is not the case.

Attitudes towards and awareness of disability

23. How do you improve awareness of the capabilities of people with disabilities?

24. How can we increase people's understanding and accommodation of invisible disabilities such as brain injury?

25. Why are disability awareness campaigns not effective?

26. How do bus drivers and other passengers treat people with disabilities?

27. Research on attitudes towards people with disabilities in employment.

28. How do you change negative attitudes on the capabilities of people with disabilities – e.g., in employment?

29. How do you get more information relating to disability in training, e.g., for designers and engineers?

30. How do you improve awareness on deafness – the ways of communicating, the culture?

31. Do retail staff have the training to develop the confidence and knowledge to engage with disabled customers?

32. What factors contribute to communities being more accepting of people with disabilities and treating people with disabilities as members of the community?

Service provision and accessibility

33. How do day services for people with disabilities perform? This is to create evidence on delivery, outcomes, performance, and to provide information on the services needed.

34. Research into people with disabilities in nursing homes.

35. How can mental health services be made accessible for deaf people?

36. How does the emergency number 112 work for deaf Irish Sign Language users and how equipped are the emergency services to respond to deaf Irish Sign Language users who use 112?

37. How accessible (or inaccessible) are health services for deaf Irish Sign Language users? For example, some GPs and out of hours urgent GPs require you to make a phone call to make an appointment.

38. How to improve access for deaf people to physical and mental health services, and to any service, amenity or resource related to health and well-being?

39. How to improve the awareness of public bodies on their duties to provide interpreters under the Irish Sign Language (ISL) Act?

40. How to penalise public services who are not compliant with their statutory duty under the ISL Act?

Accessibility and participation

41. How to improve the accessibility of government information for people with disabilities? What tools are needed? How can we build capacity e.g. reducing jargon?

42. Research to examine how accessible information is for people with disabilities.

43. How accessible is the physical environment?

44. How available is support to enable persons with disabilities participate in social and civic life?

45. How accessible are leisure centres and gyms for people with disabilities? This includes information accessibility, physical accessibility, and support to use facilities.

46. How suitable are the supports available to people with disabilities? For example, if you have impaired vision, you can apply for a reader's grant. However, with technology these days, you rarely need to pay for a reader. Instead, you need a personal assistant. Also, you are expected to pay for supports, and seek reimbursement, but people can't afford to do that.

47. How to improve access for deaf people to culture, entertainment, theatre, religion, and sport?

48. How accessible are public services and amenities for deaf people compared to private sector services and amenities?

49. What can private sector services and amenities do to improve access for deaf people?

50. How accessible are private sector services and amenities in Ireland compared to those in other countries? For example, cinemas in other countries provide subtitles at all times, but this doesn't happen in Ireland.

51. Research into the inaccessibility of products from the banking industry for those with visual impairment.

Education and employment

52. What are the opportunities for online education for everyone, including persons with intellectual disabilities?

53. How can people with disabilities access work experience and work opportunities?

54. Research the experience / preferences among people with disabilities on remote working (not everyone finds it beneficial).

55. Need ongoing monitoring to look at where/at what level people with disabilities are employed and their career progression. How many people with disabilities are at HEO/AP/PO/CEOs/SMG level (especially in organisations providing services to people with disabilities)?

56. Why is the transition to adulthood so difficult for people with disabilities? When you leave school you lose all the supports from the education system.

57. What levels of education do deaf Irish Sign Language users have in Ireland?

58. How many deaf Irish Sign Language users are in school, in college, in higher education, in university and in employment? (Would also need to know how many people in Ireland are deaf Irish Sign Language users).

59. Feasibility and impact of introducing Irish Sign Language (a national language) into the school curriculum so that children would be integrating themselves with deaf sign language users.

Community

60. Research on community spirit and community education so that the wider public help each other and those in need – the need for the wider public to be aware of anti-social behaviour, bullying of persons with disabilities, those in wheelchairs, persons with buggies etc.

61. Research on ways that people can help each other – opportunities to do positive things in the community and opportunities to do new and different things.

Mental health and wellbeing

62. Research on keeping your body healthy (including consideration of people with disabilities), as this leads to you being able to work and live independently.

63. Research on mental health and wellbeing of people with disabilities.

64. Research on the provision of support for those suffering bereavement.

65. What is the personal impact on people who are deaf Irish Sign Language users who cannot easily avail of public services, who have to repeatedly ask services to provide interpretation, who cannot conveniently use amenities like everyone else –e.g., such as the cinema?

Transport

66. What barriers are there to getting a driver's license for people with disabilities?

67. What alternative methods could be used to prove driver theory knowledge besides sitting the written theory test? This test can be difficult for people with intellectual disability, but they may have the physical ability to drive.

68. How to improve access for deaf people to public transport? For example, when a last minute change to a service is made on the loudspeaker of a train- how would a deaf person know to make the necessary change?

69. Research on creating community awareness so that people are more ready to help each other and anyone in need – being more considerate of others on public transport, facilitating accessibility, tackling bullying on public transport etc.

70. What is the impact of cycle lanes, scooters, new bus stops on people with disabilities, particularly those with sensory disabilities?

Online platforms and technology

71. What are the opportunities of technology for people with intellectual disabilities?

72. Research on the use of online platforms to avail of services.

73. Research on using online platforms for social activities.

74. Research on co-creation and co-design in fashioning suitable online education platforms for persons with intellectual disabilities. Researching how the use of these platforms are building new digital and presentation skills and how these new skills can be used to further their education, training and employment.

75. How might technology benefit the homeless?

76. Review currently available supports in light of technological advancements to ensure that supports are relevant and useful. Examine whether funding would be more usefully directed at alternative supports.

77. What are the barriers to online shopping for visually impaired people? E.g., poor website accessibility might mean you get to checkout but the payment process doesn't work with a screen reader.

78. Research into NaviLens[1] technology for people who are vision impaired.

COVID-19 pandemic

79. What was the psychological impact of the pandemic/lockdowns on people with disabilities/people with intellectual disabilities?

80. What impact did emergency measures during the COVID-19 pandemic have on the lives of disabled people?

81. How did teamwork help us get through COVID-19 pandemic?

82. Research on inequalities during the COVID-19 pandemic. For example, those with intellectual disabilities lost their jobs – they would have liked to continue working but they weren't given the opportunity to work at home or given a computer to be able to do so.

83. In what ways could persons with intellectual disabilities have continued to work during the COVID-19 pandemic?

84. Research on education for young children on making sense of the COVID-19 pandemic.

85. Research on home schooling during the COVID-19 pandemic.

Universal design

86. Research around best practice in terms of access and Universal Design, comparative studies with other countries and from the perspective of people who need access.

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[1] Footnote added by the NDA - NAVILENS is a **system of smart digital markers** that offer information through the detection and reading of these with the app.

87. How to improve accessibility with products bought from a retailer, and others we have no choice but to use? For example, the new ESB smart meter is inaccessible.

88. Where are retailers going wrong with accessibility of products when supplying visually impaired people? Some products may be accessible, but their instructions are not.

89. Do retail staff know about products that can be made accessible by the manufacturer with the addition of braille controls? Often neither the retailer nor often the manufacturer's customer service knows anything about this service.

90. What are the real reasons for situations when the manufacturer or retailer claim that the preferred service of accessibility is not available when it is?

Housing and homelessness

91. More research into the housing crisis for people with disabilities. People are living in nursing homes because they can't get accessible housing, can't get funds to retrofit their houses or make necessary adaptations.

92. What is needed to get people with disabilities living in their own houses? Many of those who receive the full grant to make their house accessible can still not afford to do it. What are the opportunities to make these things happen?

93. Research on independent living of people with disabilities.

94. Research on the homeless.

Cost of disability

95. An open transparent, advertised study on the real cost of disability, for people living with disability, regardless of payments/support they get. What actions and recommendations would follow?[2]

96. The disproportionate cost of living for visually impaired people (both blind and partially sighted) should be regularly researched.

97. Why is it so difficult for some people with disabilities to get a bank account, why do they have to pay more for insurance (e.g. for personal assistants?).

Independence

98. How can more opportunities to have self-directed care be made available?

99. How can people with disabilities who are not in a service be supported?

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[2] This suggestion was made in the context of an existing Department of Social Protection study, which was limited to people in receipt of certain social welfare payments.

Being a parent of a child with a disability

100.	Research into the information and choices given to parents when they are told their child is deaf and a consideration on how to change from a medical model approach to a social model- e.g., how to change the narrative from parents being told their child has 'failed' a hearing test and need to be 'fixed' to a more positive narrative – "these are your options…there is a deaf community out there...".

101.	Research into the experiences of hearing parents who have a deaf child/children and communication within the family.

Appendix A: Participants who submitted ideas for the NDA's Creating our Future 2021 event

Participants were informed that their names would be included in the report.

- Sabrina Barrett of St Michael's House
- Sarah Boyne of St Michael's House
- Joan Clarke
- Sandra Corr
- Catriona Crehan
- Daniel Dowling
- Elaine Grehan of the Irish Deaf Society
- Sarah Hewitt
- Elaine Howley of NCBI
- Gary Kearney
- Conor Keaveney
- Deirdre Keaveney
- Karen McCormack
- Donal O'Shea
- Nicole Redmond
- Lisa Richie

By email:

- Voice of Vision Impairment Ireland
- Fiona Weldon of Independent Living Movement Ireland

Appendix B: Voice of Vision Impairment submission for Creating our Future 2021

1. Universal Design of Products

How to improve accessibility with products bought from a retailer, and others we have no choice but to use, e.g.: the new ESB SMART METER IS INACCESSIBLE.

So, how can I seasonally switch on and off my Electric night heat heaters for the summer? Is the hive app accessible so that one can switch on the immersion etc. Will the smart meter and the hive be interactive and accessible for blind users? How can one read the reading on a smart metre? The Robinsons internet radio, is it accessible? Washing-machines, microwaves, and all phones, can now be accessible to all through audible touch-screen technology.

Research Questions

1. Where are retailers going wrong with accessibility of products when supplying visually impaired people? When products are supplied sometimes they are accessible E.G. a vacuum cleaner, a toaster, a food processor that has settings with notches but the customer is still unable to use the product when they get home because they can't read the instructions.

2. Do retail staff know about products that can be made accessible by the manufacturer with the addition of braille controls for example, washing machines, dish washers, electric and gas cookers, when often neither the retailer nor often the manufacturer's customer service, knows anything about this service.

3. What are the real reasons for situations when the manufacturer or retailer claim that the preferred service of accessibility is not available when it is, E.G. an offer of a mobile phone app instead of braille, with the claim that it is dangerous for visually impaired people to use electric rings and the company has a policy that they must use induction cookers regardless of their preferred choice.

4. Do staff have the training to develop the confidence and knowledge to engage with disabled customers?

5. What are the barriers to on-line shopping for visually impaired people? Poor descriptions on websites E.G. images without descriptive text, means that sometimes the product that is bought does not meet with the expectations of the visually impaired consumer. Poor website accessibility when using screen readers often makes a website inaccessible. Sometimes for example, it is

possible to choose an item, put it in the electronic basket, go throughout the whole of check out and then find that the payment system is inaccessible because perhaps the card needs to be selected with a mouse and not with the keyboard enter key or spacebar.

Other topics for research are Navilens[3], and Products from the banking industry which are largely inaccessible.

Finally, the disproportionate cost of living for visually impaired people (both blind and partially sighted) should be regularly researched.

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[3] Footnote added by the NDA - NAVILENS is a **system of smart digital markers** that offer information through the detection and reading of these with the app.

Appendix C: Independent Living Movement of Ireland representative's submission for Creating our Future 2021

Re research and disability:

- the use of medical model language needs to stop, research about us should embrace the social model of disability with a view of empowering disabled people and not perpetuating difference

- all related research needs to involved its main stakeholders - disabled people - they need to shape research questions and methodologies - value the lived experience

- disabled people need avenues to request research that is purposeful

- dissemination of research needs to be widened - disabled people need to be about to read/understand purpose and content, plain english/easy read/short video could support wider readership, presenting findings to disabled people would also be useful

- research about disabled people must inform both policy and practice in a meaningful way - currently this is not the case.