Report Title

Report on the public consultation for the National Disability Strategy

May 2024

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Statement on language

In this report, we use the terms ‘people/persons with disabilities’ and ‘disabled people’ interchangeably. Many people within the disability rights movement in Ireland prefer the term ‘disabled people’ because it is considered to acknowledge the fact that people with an impairment are disabled by barriers in the environment and society and therefore aligns with the social and human rights model of disability. However, we also recognise that others prefer the term ‘people/persons with disabilities’, because of the inherent understanding in the term that they are first and foremost human beings entitled to human rights and this reflects the language used in the United Nations Conventions on the Rights of Persons with Disabilities (UNCRPD). We recognise that many people with an intellectual disability, people with a mental health difficulty or psycho-social disability prefer person-first language. We also acknowledge that some people do not identify with either term.

In this report, the term ‘Deaf’ with an uppercase ‘d’ is used when referring to those who are Deaf or hard-of-hearing who identify culturally and linguistically as part of the Deaf community and who use Irish Sign Language as their first or preferred language. A lower case ‘d’ is used to refer to those who are deaf or hard-of-hearing and who do not identify culturally and linguistically as a member of the Deaf community. The term ‘d/Deaf’ is used to refer to both groups.

The term Disabled Persons’ Organisation (DPO) is used in this report, but we acknowledge that some DPOs may prefer the term Disabled Persons’ Representative Organisation (DPRO).

For further information on disability-related language and terminology, please refer to the NDA’s [Advice Paper on Disability Language and Terminology](https://nda.ie/publications/nda-advice-paper-on-disability-language-and-terminology) on nda.ie.

List of acronyms

AAC Augmentative and Alternative Communication

ADHD Attention Deficit Hyperactivity Disorder

ADMA Assisted Decision Making (Capacity) Act

AT Assistive Technology

CAMHS Child and Adolescent Mental Health Services

CDNT Children’s Disability Network Team

CEFR Common European Frame of Reference

CHO Community Healthcare Organisation

CODA Child of Deaf Adult

CSO Central Statistics Office

CPD Continuing Professional Development

DA Disability Allowance

DARE Disability Access Route to Education

DCD Developmental Co-ordination Disorder

DCEDIY Department of Children, Equality, Disability, Integration and Youth

DPO Disabled Persons’ Organisation

DPRO Disabled Persons’ Representative Organisation

DSG Disability Stakeholder Group

EPSEN Education for Persons with Special Educational Needs [Act]

FET Further Education and Training

HAP Housing Assistance Payment

HEAR Higher Education Access Route

HIQA Health Information Quality Authority

HSE Health Service Executive

IEP Individual Education Plan

ISL Irish Sign Language

LGBTQI+ Lesbian Gay Bisexual Transgender Queer Intersex plus

NASS National Ability Support System

NCSE National Council for Special Education

NDA National Disability Authority

NDIS National Disability Inclusion Strategy

NDS National Disability Strategy

NEPS National Educational Psychological Service

NGO Non-Governmental Organisation

NTA National Transport Authority

OECD Organisation for Economic Cooperation and Development

PA Personal Assistant

RISLI Register of Irish Sign Language Interpreters

SDG Sustainable Development Goal

SLIS Sign Language Interpreting Service

SNA Special Needs Assistant

SUSI Student Universal Support Ireland

UNCRC United Nations Convention on the Rights of the Child

UNCRPD United Nations Convention on the Rights of Persons with Disabilities

WSS Wage Subsidy Scheme

Executive summary

# ES1 - Introduction

This report presents the findings from the public consultation for the new National Disability Strategy which took place from November 2023 to February 2024. The Department of Children, Equality, Disability, Integration and Youth (DCEDIY) requested support from the National Disability Authority (NDA) to carry out a comprehensive public consultation to inform the new strategy. The National Disability Strategy is the successor strategy to the National Disability Inclusion Strategy 2017-2022.

Ireland ratified the UN Convention on the Rights of Persons with Disabilities (UNCRPD) in 2018, committing to promote the human rights of all disabled people in Ireland. The new National Disability Strategy will seek to provide a blueprint for further realisation of the UNCRPD. In line with the ethos of the UNCRPD, the consultation focused on identifying actions and solutions to address challenges and barriers to participation in society faced by disabled people.

Throughout the course of the consultation, the NDA regularly shared emerging findings with DCEDIY to help inform the ongoing development, approach and content of the new National Disability Strategy.

# ES2 - Methodology

The consultation was underpinned by principles of participation and aimed to be a genuine, accessible, and transparent process which meaningfully engaged with disabled people. During the consultation the NDA and DCEDIY proactively sought and gave due consideration and priority to the opinions and views of DPOs. Specific DPO contributions are noted in this report for easy identification and consideration by policy makers as part of the strategy development process.[[1]](#footnote-2) Issues and areas identified as key priorities by DPOs and other disability stakeholders during engagements with DCEDIY in 2023 were used to inform, facilitate, and guide the consultation questions.

In addition to DPOs, people with disabilities and other disability stakeholders including families, parents, carers, and disability organisations were targeted and actively encouraged to participate in the consultation. Marginalised and seldom heard-from groups, such as disabled children and people with significant support needs were specifically included. Acknowledging the intersectionality of disability with other identities[[2]](#footnote-3), women, migrants, Travellers, and members of the LGBTQI+ community were specifically targeted for consultation. A range of consultation activities were organised to allow different stakeholders choice in how they could engage. Consultation events were held at various times of the day, and during weekdays and the weekend.

Disability stakeholders engaged in consultation activities including:

* 34 focus group discussions involving 211 participants,
* 18 interviews with disabled individuals,
* Four large consultation meetings in Dublin, Cork, Galway, and online, including 166 attendees,
* 81 written and 4 video submissions from DPOs, disability organisations, individuals, and other interest groups,
* A national survey completed by 484 disabled people or carers, family members and supporters of people with disabilities.

Qualitative and quantitative data were collected across consultation activities. Data were analysed to identify the challenges, barriers, actions, and solutions raised by consultation participants.

# ES3 - Survey findings on quality of life and disability awareness

The consultation survey aimed to identify the issues most important to disabled people’s quality of life and to explore how people with disabilities feel they are treated. The three issues rated as important to their quality of life by the highest proportion of respondents were:

* getting health or social care services and supports,
* having enough money to cover the extra costs related to their disability,
* being able to get and use public or private transportation easily.

Respondents reported that family and friends were the groups most likely to be reported as having enough disability awareness, whereas the general public were reported as least likely to have enough disability awareness. Of concern is that 62% of disabled survey respondents felt that health and social care staff were not aware enough of their disability. In addition, people providing public services such as social protection, local authority, and public transport staff were most likely to be identified as treating people negatively because of their disability.

There was general alignment between the issues most commonly rated as important to disabled people’s quality of life by survey respondents and the frequency with which these issues were raised across other consultation activities. The survey findings indicate that there is a need for impactful, widespread awareness raising campaigns on disability, as well as targeted disability competence training for public service staff, employers, and health and social care staff.

# ES4 - Feedback on strategy development, implementation, and monitoring

Consultation participants provided a wealth of feedback and recommendations about ongoing stakeholder engagement in the strategy, as well as strategy development, implementation, and monitoring.

## ES4.1 Stakeholder engagement

Participants suggested that the strategy needs:

* to put disabled people and DPOs at the centre of any engagement structure or monitoring structure from the beginning,
* accessible information and communication regarding engagement,
* regular, genuine, and transparent engagement between government departments and disabled people throughout the lifetime of the strategy,
* to support and build the capacity of people with disabilities to engage,
* a flexible, proactive and grassroots approach to engagement.

## ES4.2 Strategy development

### Strategy vision

Participants emphasised that the vision of the strategy should be underpinned by a social model orientation and human rights approach, should use active language and Plain English, and should not rely on what some felt were ‘buzzwords’ like ‘inclusion’ and ‘diversity’. There was a sense that these terms can be used as a ‘catch-all’ without any clarity as to what they translate to in reality, and that they are used so often they may have lost some of their original meaning and power.

### Values underpinning the strategy

Participants called for the strategy to be underpinned by the values of respect, dignity, collective empowerment, collaboration, innovation, accountability, empathy, affirmation, autonomy, sustainability, flexibility, belonging and inclusion.

### Principles underpinning the strategy

They felt that the strategy should retain the principles from the UNCRPD (Article 3) to demonstrate a commitment to the UNCRPD framework. In addition to considering the merits of these principles, they felt the strategy should also be underpinned by principles of ‘Nothing About Us, Without Us’ and Accountability.

### Pillars of the strategy

Participants were asked whether they felt the following five original draft pillars of the strategy were appropriate:

* employment and anti-poverty,
* transport and mobility,
* independent living in the community,
* wellbeing and social care services,
* education and training.

In response, consultation participants:

* Expressed a preference for placing the disabled person at the centre of the pillars, rather than designing the pillars around the structure of government departments;
* Generally felt that ‘employment and anti-poverty’ should be separated into two pillars particularly as a person could be employed and living in poverty;
* Were confused as to what the ‘independent living in the community’ pillar would include;
* Raised concerns regarding the wording of ‘wellbeing and social care services’, in particular the paternalistic connotations of the word ‘care’;
* Queried where issues they deemed important, such as health, mental health, and housing would sit; and
* Queried where cross-cutting issues would sit within the original draft pillars, such as accessibility, communication, disability equality training, human rights, and Universal Design.

## ES4.3 Strategy implementation, monitoring, oversight, and accountability

Participants expressed disappointment at the implementation of previous national strategies, which they felt had over-promised and under-delivered, and for which there was a perceived lack of transparency and accountability. To counter this for the National Disability Strategy, participants called for:

* A whole-of-government approach to strategy development and delivery;
* A focused list of measurable and achievable actions, with clear timelines and ownership;
* Prioritisation of actions to be determined by disabled people;
* A sustained focus on implementation;
* Realistic targets and defined indicators of progress;
* Strategy alignment with other relevant strategies and policies;
* Appropriate monitoring and oversight mechanisms which involve disabled people; and
* High-level accountability where implementation stalls.

# ES5 - Challenges and proposed solutions

Across all the consultation activities, consultation participants discussed challenges that disabled people face in society, and proposed actions and solutions to address these challenges. The following is a summary of the main challenges and key actions proposed by participants in a number of topic areas. Please note the full report covers these challenges and their related proposed actions in greater detail.

## ES5.1 - ‘Nothing About Us, Without Us’

Participants called for disabled people and their representative organisations to have more control in the decisions that affect their lives. They raised challenges including limited funding and resourcing to facilitate DPO involvement in decision-making processes, and that not all disabled people can self-advocate or have access to appropriately resourced DPOs to promote their interests. Linked to these issues, there were calls to address barriers for people with disabilities in political life.

Key proposed actions and solutions to address challenges include:

* Build DPO capacity by supporting and funding DPOs;
* Establish DPOs for people with more significant support needs and for children with disabilities;
* Prioritise and distinguish views of DPOs (over non-DPOs) through creating a DPO register;
* Include DPOs in the consultative process from the outset of any new policies being introduced in Ireland;
* Ensure transparency from government departments about how consultations impact their decision-making processes; and
* Ensure all government departments have disability representation.

## ES5.2 - Awareness, attitudes, and discrimination

Many participants spoke of their experiences of prejudiced attitudes and discrimination and how this can have a profound negative impact on the well-being of disabled people. They explained how these attitudes arise from lack of visibility and understanding of disability in society and how particular disability experiences are being omitted from awareness campaigns.

Key proposed actions and solutions to address these challenges include:

* Actively tackle inadequate disability awareness and ableism through public awareness campaigns;
* Deliver disability equality training to anyone delivering mainstream and disability-specific services to disabled people;
* Promote the visibility of disabled people in public life and in communities;
* Deliver disability equality training to children and young people in schools; and
* Ensure positive representation of disabled people on radio, television, podcasts, and in newspapers that challenges stereotypes, guarding against ‘pity’ narratives and ‘toxic positivity’.

## ES5.3 - Accessibility

The importance of accessibility for equality, realisation of rights, independence, community participation, and belonging were emphasised. Participants cautioned against narrow understandings of ‘access’, and advocated for a holistic approach that addresses not only physical barriers but also communication, information, and digital access barriers. They also referred to the critical importance of assistive technology (AT) in facilitating their access to education, employment, and independent living. AT was characterised as a human right and a precondition for community participation, supporting communication, rehabilitation, independence, and improved quality of life.

Key proposed actions and solutions to address these challenges include:

* Make all public buildings accessible (to people with physical, sensory and psychosocial disabilities), regardless of cost;
* Fund businesses and community groups to make premises accessible;
* Develop accessible cities, towns and villages, and a focus on accessibility in rural areas;
* Create more accessible public toilets and increase availability of Changing Places toilets;
* Clear paths, roadways, car parks from street furniture and other obstacles and impose penalties for those causing obstructions;
* Provide more accessible information, websites and services (easy read, video, ISL, braille) across a range of areas;
* More access to and increase in availability of ISL interpreters;
* Invest significantly in assistive technology, both in the technologies themselves and the services/supports to ensure that those who need them can get them in a timely manner; and
* Provide AT to individuals, not organisations.

## ES5.4 - Health and social care services

Health and social care services was by far the most common topic raised throughout the consultation. Participants reported challenges and barriers to accessing assessments, services and supports, including a failure to deliver or a lack of availability of services, long waiting lists, and geographic variations in the provision and quality of services. Many of these difficulties were attributed to a lack of adequate funding and staffing, including a lack of multi-annual funding for voluntary organisations providing services on behalf of the state. A range of cross-cutting issues were identified including difficulties accessing information and signposting on services, supports and entitlements, lack of forecasting and planning for future care needs, and lack of understanding of disabled people amongst health and social care professionals. Some of the primary concerns raised during the consultation process related to barriers to early intervention services, multidisciplinary supports, children’s therapies, and respite services for both children and adults with disabilities. Participants also drew attention to insufficient services and supports in other areas, including adult and children’s mental health services, adult therapies, residential care, day services, assistive technology, and home care.

Key proposed actions and solutions to address these challenges include:

* Ensure that all disabled people have equal and consistent access to and are provided with health and social care services in a timely manner.
* Eliminate any geographic disparities in the provision of care and services;
* Provide health and social care services based on assessed current and future needs;
* Foster a joined-up approach across health and social care services to ensure that disabled people do not fall between the cracks;
* Ensure that all health and social care services are fully accessible to disabled people and are universally designed;
* Provide more accessible information regarding health and social care services and better signposting towards supports;
* Ensure that health and social care professionals understand and are aware of the diverse needs of disabled people;
* Increase funding for health and social care services to ensure disabled people have timely and equal access to supports;
* Provide multi-annual funding to organisations providing health and social care services on behalf of the State;
* Increase staffing within health and social care services, specifically day, residential, respite and children’s disability services, to meet needs;
* Increase the provision of respite services for both adults and children with disabilities;
* Ensure disabled people have regular, consistent, and adequate access to home care support;
* Ensure that children’s disability services are adequately resourced;
* Improve early intervention services and supports for disabled children;
* Provide timely access to therapies and services to all children who require them on an ongoing basis;
* Provide more mental health and counselling supports to children and ensure access to Child and Adolescent Mental Health Services (CAMHS) for all children and young people with disabilities, including those with intellectual disabilities and/or who are autistic; and
* Address mental health issues within the Traveller Community e.g., ensure quicker referrals to CAMHS for Traveller children.

## ES5.5 - Independent living

Consultation participants emphasised choice, control, and support as key factors in achieving independence and community participation. The main challenges to independent living included barriers to accessing personal assistance, control of one’s own finances and inaccessible environments. Participants urged the government to listen to people with disabilities about where and with whom they wish to live.

Key proposed actions and solutions to address these challenges include:

* Implement and fund a proper personal assistance service;
* Introduce personalised budgets to individuals on a national, permanent basis;
* Improve access to home help or care services to promote independence and reduce reliance on family member for personal care;
* Plan and fund the exit strategy for young people (<65 years) in nursing homes;
* Increase access to a range of in-home, residential and community supports; and
* Develop a national plan to realise the right to independent living as part of the over-arching policy framework.

## ES5.6 - Housing

Major challenges raised concerned barriers to available, accessible, and affordable housing as well as the impact this has on the wellbeing of people with disabilities. Challenges related to housing applications, grants, benefits, and entitlements were also raised.

Key proposed actions and solutions to address these challenges include:

* Build more universally designed housing stock;
* Update minimum requirements for accessibility in rented accommodation;
* Widen the income threshold eligibility cut-off point for social housing;
* Prioritise the availability and allocation of different housing options for persons with disabilities on the basis of need;
* Implement joined-up services with HSE and local authorities to ensure social care needs are provided for in tandem with housing needs; and
* Plan for the long-term housing needs for people with complex needs rather than waiting for emergencies to happen.

## ES5.7 - Education and training

The major issue raised by participants about education and training concerned the need for more support and resources for inclusive education practices. Consultation participants reported low expectations for students with disabilities, different standards of inclusive practices, and a lack of teachers with appropriate support and training for inclusive educational practices. Participants also stressed the challenges and barriers that disabled people face transitioning within and between educational, training and employment settings. Participants reported unique challenges for different disability groups such as Deaf people, those with intellectual disabilities, neurodivergent people as well as women, Travellers, and asylum seekers with disabilities.

Key proposed actions and solutions to address these challenges include:

* Employ a child-centred, rights-based, inclusive educational model underpinned by the ethos of the UNCRPD to adapt educational environments to people’s needs rather than expect disabled people to adapt to fit the environment;
* Improve supports and resources for inclusive education practices including specialists, information, funding, and appropriate spaces;
* Highlight and share examples of good inclusive education practices;
* Ensure every student (disabled or non-disabled) in special school or mainstream settings receives tailored career guidance;
* Ensure continuity of accommodations for students with disabilities;
* Embed disability awareness/equality training in schools;
* Deliver inclusive sex education in schools;
* Create more places for autistic and neurodiverse children in mainstream schools; and
* Ensure every Deaf child has a fully qualified ISL special assistant teacher.

## ES5.8 - Employment

Across the consultation, the importance of employment for inclusion, independence, and social and economic well-being was emphasised. The importance of recognising that some disabled people will not be able to work and must not be pressured to do so was also stressed. Consultation participants described general barriers to employment for disabled people in Ireland, and how challenges specific to different groups should be addressed in the strategy. Challenges on the side of employers included inaccessible recruitment processes, lack of reasonable accommodations and discriminatory attitudes. Other barriers to employment included lower educational attainment, issues with social welfare services and schemes, and returning to sustainable employment after leaving as a result of acquiring a disability.

Key proposed actions and solutions to address these challenges include:

* Develop accessible recruitment processes;
* Improve disability competence among employers;
* Produce more incentives for employers to hire disabled people;
* Improve access to reasonable accommodations and a more flexible Reasonable Accommodations Fund;
* Develop an easier route back to Disability Allowance (DA) if employment does not work out for people with disabilities;
* Retain secondary benefits such as the medical card and free travel pass for disabled people who move from DA to employment;
* Create specific, measurable targets for the employment of disabled people;
* Improve employment supports, including support to find suitable employment and in-work supports such as personal assistance and ISL interpretation;
* Introduce a national policy and system for vocational rehabilitation; and
* Raise the public sector minimum employment target and extend this target to NGOs and the private sector.

## ES5.9 - Financial independence and security

The main challenges relating to financial independence and security were the extra cost of disability and increased risk of poverty for disabled people. Participants deemed social protection measures as inadequate for a decent standard of living, with some noting their frustration that Disability Allowance (DA) is less than the initial Pandemic Unemployment Payment. Means-testing supports was felt to be punitive to families with disabled family members.

Key proposed actions and solutions to address these challenges include:

* Introduce a permanent, non-means-tested, non-taxed cost of disability payment (separate to social welfare payments);
* Increase social protection payments;
* Abolish means-testing of benefits and entitlements;
* Give automatic entitlement to the medical card for all people with a disability;
* Make eligibility criteria for benefits and entitlements more inclusive; and
* Improve applications, appeals and reviews processes to make the process more accessible.

## ES5.10 - Transport and mobility

Transport was seen as a key enabler of independence, social inclusion and access to employment and education, particularly for people with disabilities living in rural areas. The main challenges raised included insufficient and inaccessible forms of public and private transport, and a failure to include DPOs and disabled people in decisions about transport.

Key proposed actions and solutions to address these challenges include:

* Make more accessible, affordable, and available public and private transport;
* Improve joined-up thinking within transport services;
* More wheelchair spaces on buses;
* Remove requirement to pre-book public transport;
* Provide accessible communications on public transport;
* Increase the number of accessible taxis;
* Consider views of disabled people when designing active travel infrastructure and prioritize safety for all;
* Reinstate the Motorised Transport Grant and the Mobility Allowance and make mobility schemes more flexible; and
* Amend the requirements for the Disabled Drivers and Passengers Scheme including the appeals process.

## ES5.11- Culture, recreation, leisure, and sport

It was evident during discussions that opportunities for leisure, recreation, sport, and access to the arts and culture had a positive impact on people’s quality of life. Barriers to participation in culture, recreation, leisure, and sport included inaccessible facilities and transportation to, for example, sports clubs, entertainment venues, bars and hotels. Specific challenges for LGBTQI+ disabled communities and d/Deaf communities were also highlighted by participants.

Key proposed actions and solutions to address these challenges include:

* Encourage social venues to offer more accessible services, information and spaces;
* Provide Changing Places toilets in shopping centres, hotels, cinemas, and swimming pools;
* Support the establishment of more community groups to enable people with disabilities to meet like-minded individuals who share similar hobbies/interests;
* Introduce a transport allowance to facilitate access to social communities and health and fitness initiatives/centres;
* Provide funding to make LGBTQI+ resource centres and community spaces accessible; and
* Continue the ISL voucher scheme which provides free access to ISL interpreters for a variety of events, services, and activities.

## ES5.12 - The justice system

Consultation participants noted challenges related to the accessibility of the legal, international protection and prison systems for disabled people and highlighted the importance of diverting people with mental health issues away from the criminal justice system.

Key proposed actions and solutions to address these challenges include:

* Ensure the courts system is accessible to all, by providing reasonable accommodations and assistive technology, appointing intermediaries or court mentors, and nominating access officers;
* Provide training to legal professionals on disability awareness and rights, and effective communication with disabled people;
* Support and gather accurate and timely data on the nature and prevalence of disability among people in custody;
* Ensure the rights of disabled asylum seekers to access and participate in all asylum proceedings, including the international protection determination process, and provide any necessary reasonable accommodations; and
* Introduce legislation and other initiatives that support the effective diversion of people with severe mental health issues from the penal system.

## ES5.13 - Abuse and violence

Consultation participants noted that disabled people can experience higher levels of abuse and violence due to factors like financial barriers to leaving abusive situations. Other challenges related to hate crime and sexual violence.

Key proposed actions and solutions to address these challenges include:

* Ensure accessible supports for disabled victims of abuse and violence;
* Enhance cooperation between victim support and disability organisations; and
* Enact effective hate crime legislation.

## ES5.14 - UNCRPD implementation and disability legislation

Consultation participants highlighted concerns regarding the lack of effective implementation of the UNCRPD, with many referencing the ongoing delay in ratifying the Optional Protocol and divergences between disability-related legislation and UNCPRD standards. Proposed actions include to ratify the Optional Protocol and review all legislation concerning disability rights to ensure full alignment with the UNCRPD.

## ES5.15 - Data and research

Participants stressed that more high-quality disability data needs to be collected that can be disaggregated to develop targeted and effective policies that consider the multiple identities of different groups.

Key proposed actions and solutions to address these challenges include:

* Fully resource the Central Statistics Office (CSO) to collect relevant, disaggregated, and timely data to inform future policy development;
* Include the lived experience of people with disability in data collection through funding for inclusive research initiatives; and
* Ensure data collection on disability takes an intersectional approach, specifically for Travellers, LGBTQI+ people, children, and the prison population.

## ES5.16 - Climate justice, situations of risk and humanitarian emergencies

Several consultation participants referred to issues of climate justice for disabled people. They referenced the negative consequences of the climate crisis for disabled people and were conscious of the risks facing people with disabilities during situations of risk and humanitarian emergencies. Participants recommend that any climate adaptation and mitigation, and disaster preparedness approaches include the views of people with disabilities and their representative organisations at a local level.

## ES5.17 - International co-operation

Participants wanted Ireland to demonstrate commitment to disability inclusion in its overseas development work and engage on global issues such as the Global Disability Summit and Inclusive Humanitarian Charter.

# ES6 - Caring for and supporting people with disabilities

During the consultation, participants emphasised the importance of acknowledging families and carers in the new National Disability Strategy. There was a clear message from the consultation that carers feel unsupported by the State. Carers noted that they feel invisible, and their value is not acknowledged, particularly when they are not paid for their caring role or are paid a small amount due to means testing and taxing of financial support. The main challenges raised for carers included the lack of respite available nationwide and the lack of any mechanism to enable parent carers to plan for their children’s futures. In addition, many participants referred to the financial challenges of caring for someone with a disability in Ireland and some highlighted specific issues related to the Travelling Community such as a gender imbalance in the burden of care.

Key proposed actions and solutions to address these challenges include:

* Recognise care and support provided by including families, carers and supporters within the language of the strategy;
* Improve provision of respite for disabled children and adults;
* Develop a mechanism to plan for future care including discussions with people with disabilities and carers and joined-up thinking to plan clear pathways to address future needs;
* Reform the current system of benefits and entitlements for carers by increasing the level of financial support to carers (e.g., Carer’s Allowance) and removing means testing and taxing of financial supports;
* Improve supports for carers by providing targeted and tailored family support packages for parents and carers of those with disabilities to support resilience and wellbeing;
* Provide a service for carers which includes counselling and advocacy training; and
* Include a consideration of intersectionality – for example, the likelihood that a higher proportion of female Travellers are carers than settled females.

# ES7 - Conclusion

The purpose of this report was to summarise the breadth of the contributions made and the solutions suggested by a wide range of disability stakeholders. Unfortunately, it will not be possible for all contributions to be included in a new strategy. However, this report is an extremely valuable record of the concerns and suggestions of Disabled Persons’ Organisations, disabled people, their families, service providers, civil society organisations, advocacy bodies and carers. While the key purpose of this document is for use in developing the new NDS, we encourage stakeholders to use this report to inform reporting ahead of Ireland’s first examination under the UNCRPD, to shape the national disability research agenda and government policies, and to inform other government strategies and action plans more generally. When considering the recommendations in this report, we encourage people to be inclusive of children, young people and adults with disabilities, and those with intersectional identities. We look forward to the new NDS, informed by this report, that will promote the human rights of all disabled people in Ireland.

1. Introduction

Ireland ratified the UN Convention on the Rights of Persons with Disabilities (‘UNCRPD’ or ‘Convention’) in March 2018. By ratifying the Convention, Ireland committed to promoting and protecting the full enjoyment of all human rights by people with disabilities.

The Convention emphasises that disabled people, through their representative organisations, must be consulted and actively involved in the development, implementation and monitoring of policies and legislation, as well as other decision-making processes. The Department of Children, Equality, Disability, Integration and Youth (DCEDIY) therefore sought to ensure that the development of a successor strategy to the National Disability Inclusion Strategy 2017-2022 would be informed by a comprehensive public consultation process, in line with the principle of ‘Nothing About Us, Without Us’.[[3]](#footnote-4)

DCEDIY requested support from the National Disability Authority (NDA) with the consultation process. The NDA is the independent statutory body providing evidence-based advice and research to Government on disability policy and practice and promoting Universal Design. DCEDIY led on engagement with Disabled Persons’ Organisations (DPOs)[[4]](#footnote-5) and on national and regional consultation meetings. The NDA led on all other aspects of the consultation, including online and in-person focus group discussions, a national survey, written and video submissions, and commissioned consultations with seldom-heard-from children and adults with disabilities.

The new National Disability Strategy will seek to provide a blueprint for further realisation of the UNCRPD by identifying and implementing key actions which aim to ensure that disabled people in Ireland are fully included in society, in line with the vision of the Convention. The consultation was therefore solution-focused, with participants invited to suggest actions for inclusion in the strategy and survey participants asked to prioritise areas they felt deserved most focus.

In line with Article 4.3 of the UNCRPD[[5]](#footnote-6) and informed by the Committee’s General Comment No.7 [[6]](#footnote-7),there is a requirement to meaningfully consult and involve DPOs and give due consideration and priority to the opinions and views of DPOs when addressing issues directly related to persons with disabilities. The NDA proactively sought the views of DPOs during the consultation process, and DPO contributions are marked as such throughout the report for easy identification and consideration by policy makers as part of the strategy development process. This is in addition to extensive consultations carried out by DCEDIY with DPOs. The consultation process aimed to be as inclusive as possible, specifically targeting seldom-heard-from adults and children with disabilities, people with disabilities who also have other marginalised identities, and older people with disabilities. Many events were held online to facilitate those for whom travel may have caused a difficulty, while a number of interviews, focus groups, and consultation meetings were held in person across the country. Events were held at various times of the day, and during weekdays and the weekend to facilitate those who are working, who have caring responsibilities and who had to travel.

The purpose of this consultation report is to summarise the breadth of the contributions made and the solutions suggested to the challenges disabled people are facing. It is not possible for all of these contributions to be included in a new strategy which aims to focus on high level impactful actions. However, they are an extremely valuable record of the concerns of Disabled Persons’ Organisations, disabled people, their families, civil society organisations, advocacy bodies, carers and service providers. We encourage stakeholders to use this report to inform reporting ahead of Ireland’s first examination under the UNCRPD, to shape the national disability research agenda and government policies, and to inform strategies and action plans more generally.

# 1.1 Structure of the report

The structure of this report is as follows:

* Chapter 2 describes the methodology of the consultation, including information on participants and specifics on the consultation activities, as well as a brief explanation of how the feedback collected was analysed;
* Chapter 3 provides descriptive statistics from respondents to the consultation survey. The areas covered include the issues of importance to respondents’ quality of life at present, how aware others are of their disability, and whether they feel they are treated differently by others because of their disability;
* Chapter 4 describes consultation participants’ feedback to Government on the vision, values, and principles which should underpin the strategy, and how the strategy could be developed, implemented, and monitored, particularly with the involvement of DPOs and other disability stakeholders;
* Chapter 5 summarises the wealth of information provided by participants across all elements of the consultation, focusing on proposed solutions to address the challenges experienced by people with disabilities in Ireland. In this chapter, the following seventeen topics are addressed:
  1. ‘Nothing About Us, Without Us’
  2. Awareness, attitudes, and discrimination
  3. Accessibility
  4. Health and social care services and supports
  5. Independent living
  6. Housing
  7. Education and training
  8. Employment
  9. Financial independence and security
  10. Transport and mobility
  11. Culture, recreation, leisure, and sport
  12. The justice system
  13. Abuse and violence
  14. UNCRPD implementation and disability legislation
  15. Data and research
  16. Climate justice, situations of risk, and humanitarian emergencies
  17. International cooperation;
* Chapter 6 summarises the information provided by those who care for people with disabilities which focusses on proposed solutions to address to the challenges they experience;
* Chapter 7 provides a conclusion; and
* Appendix A provides a list of the organisations who made written or video submissions to the consultation.

During the consultation many participants made, or provided links, to reports, videos, submissions and other materials to reinforce the points they were making. These have been collated into a separate document along with a summary of key documents related to disability issues over the past five years.[[7]](#footnote-8)

1. Methodology

Between mid-November 2023 and early March 2024, a range of consultation activities were undertaken. These were designed to allow stakeholders choice and flexibility in how they could engage in the consultation. The consultation was underpinned by principles of participation and collaboration and aimed to be a genuine, accessible, and transparent process which meaningfully engaged disabled people.

A communications campaign about the consultation was launched, which included regular notifications on the NDA website and on a dedicated gov.ie UNCRPD website. NDA and DCEDIY social media platforms were also used along with advertisements on community engagement websites, the gov.ie consultations website and targeted e-mails to stakeholders. Stakeholders were also encouraged to share calls to participate in the various consultation activities with their networks. In line with Article 4.3 of the UNCRPD and the principles outlined in the UN Committee’s General Comment No.7, this consultation actively involved persons with disabilities, through their representative organizations or Disabled Persons’ Organisations (DPOs). Other disability stakeholders including people with disabilities, families, parents, carers, and disability organisations were targeted and actively encouraged to participate in the consultation. Marginalised and seldom-heard-from groups were specifically targeted and approached to participate in the consultation.

Details of public consultation activities were advertised to stakeholders in accessible formats, including Irish Sign Language (ISL) and Easy to Read formats, as well as in the Irish language. All in-person and online events offered ISL interpreters and real-time captioning. In-person consultation meetings were held in accessible locations, and mobile Changing Places toilets were made available in two out of three of these meetings. The national survey was written in plain language and was available in different formats, including an online survey with ISL videos, an Irish language version, a version adapted for screen readers, and Easy to Read versions, as well as a paper survey (plain language and Easy to Read versions), and a telephone option.

# 2.1 Consultation activities

## 2.1.1 Focus groups and interviews

A series of focus groups and interviews was carried out to capture actions and solutions to barriers and challenges to participation in society for disabled people. A total of 25 online and nine in-person focus group discussions were held, each lasting from 1 to 1.5 hours. Eighteen interviews were conducted with individuals with disabilities, 14 of these were face to face, three were online, and one was by telephone. Some 219 people took part in an interview or focus group, of which 8% were DPO representatives (n=17) and over one quarter (n=58, 27%) represented other organisations. Over half of focus group and interview participants (58%, n=126) were women, and we estimate that almost three quarters were people with a disability. Parents, carers, and other interested members of the public also participated. Most focus groups were facilitated by NDA staff with an introduction provided by a member of the DCEDIY Disability Equality Policy unit. ACE Communication was contracted to conduct focus groups and interviews with disabled people who are seldom heard from, including children and young people and adults with specific communication needs.

Thematic focus groups were conducted, as were targeted focus groups and interviews with key groups. Issues identified as key priorities by DPOs and other disability stakeholders during engagements with DCEDIY in 2023 were used as the themes for the following online focus groups:

* transport,
* employment and training,
* education,
* health and social care services,
* cost of disability,
* housing and independent living.

The targeted focus groups and interviews aimed to capture the perspectives of disability stakeholders who are seldom heard from, who have other marginalised identities and experience unique barriers to their participation in society, as well as carers of people with disabilities. These included specific focus groups and interviews for:

* Deaf people,
* older people with disabilities,
* disabled women,
* Travellers,
* asylum seekers,
* LGBTQI+ people,
* carers,
* people with intellectual disabilities and/or autism (focus groups and interviews conducted by ACE communication),[[8]](#footnote-9)
* children and young people with disabilities (focus groups and interviews conducted by ACE communication)[[9]](#footnote-10) – in some cases children/young people used communication devices to participate, and others were supported with Lámh signs.

Down Syndrome Ireland (DSI) and Inclusion Ireland (II) also supported the inclusion of people with disabilities in the consultation by conducting their own focus groups and interviews, with support provided by the NDA. These consultations comprised:

* one online focus group with six adults with Down syndrome (DSI),
* one in-person focus group with eights adults with ID (II),
* in-person interviews with three adults and two children with ID who have significant support needs (II). These participants could not fully rely on speech to communicate, three of them used some ‘mouth words’ during the interviews, and all communicated through vocalising, facial expressions, body movements and sound. One of the participants was learning to use a high-tech AAC device to communicate.

## 2.1.2 Consultation meetings

During the consultation period, DCEDIY hosted four consultation meetings, with support from the NDA. Two of these were national meetings held in Dublin and online and two were regional, held in Galway and Cork. In total, 166 people attended these events, including individuals and representatives of 96 organisations and 17 participants representing DPOs. The topics explored during focus groups and interviews were also discussed in these meetings, as were the topics of meaningful stakeholder engagement and the strategy’s possible vision, values, and principles.

During focus groups, interviews, and consultation meetings, there was also space for participants to raise other issues of interest to them.

## 2.1.3 Written and video submissions

A public call was issued seeking written or video submissions from organisations and individuals to provide input to the strategy. Eighty-one written submissions and four video submissions were received including:

* 8 from DPOs,
* 12 from disabled individuals,
* 25 from other disability organisations,
* 8 from carers,
* 32 from other interest groups such as academic institutions or organisations working with marginalised groups.

Please note that all written submissions and transcripts of video submissions have been provided to DCEDIY for their reference. See Appendix A for a list of organisations who made submissions.

## 2.1.4 National survey

A national survey was developed to capture the views of disabled people and carers/parents/supporters on what the strategy should include and prioritise based on their experiences. Disabled people were also asked about issues important to their quality of life, about how they feel they are treated and how their disability is understood by people in their lives.

Three DPOs provided input on the wording of survey questions. The online survey (in its various formats) was live for one month, and flexibility in the closing date was allowed for reasonable accommodations.

Overall, 484 people responded to the survey. Almost three quarters of respondents were disabled people (n=358, 74%) and one third were carers/parents/supporters of people with disabilities (n=162). Seven percent of respondents were both disabled and carers/parents/supporters of people with disabilities (n=36). It should be noted that as this survey is a sample of disabled people, carers, and disabled carers, we cannot generalise the findings from this survey to all disabled people and carers in Ireland.

### Disabled people

Seventy percent of survey respondents with disabilities were women (n=249), 25% were men (n=91) and 3% identified as another gender (n=9).[[10]](#footnote-11) One in ten disabled respondents was aged 18-24 (n=34, 10%), almost half were between 25 and 49 years old (n=171, 48%), around one third were aged 50-64 (n=113, 32%) and 8% were aged 65 or older (n=30). Approximately one third of disabled respondents lived in a city (n=120, 34%), just over one in five people lived in a big town (n=79, 22%), almost one quarter lived in a small town (n=85, 24%), and one fifth lived in a rural area (n=71, 20%).

Survey respondents were asked about their long-lasting conditions or difficulties.[[11]](#footnote-12) A breakdown of their responses is provided in Table 1, presented from most to least common. Almost three quarters of respondents had multiple disabilities (n=265, 74%).

Table 1. Long-lasting conditions or difficulties breakdown for disabled survey respondents

|  |  |  |
| --- | --- | --- |
| Long-lasting condition or difficulty | Number of disabled respondents  N=358 | % of disabled respondents |
| A difficulty with learning, remembering or concentrating | 161 | 45 |
| A difficulty with basic physical activities such as walking, climbing stairs, reaching, lifting or carrying | 159 | 44 |
| A psychological or emotional condition or a mental health issue | 138 | 39 |
| A difficulty with pain, breathing or any other chronic illness or condition | 127 | 35 |
| Visual impairment | 103 | 29 |
| An intellectual disability | 86 | 24 |
| Deaf or hard of hearing | 66 | 18 |
| Autism/Attention Deficit Hyperactivity Disorder (ADHD)/Neurodivergent (category developed from open-ended responses) | 28 | 8 |
| Dyslexia/Dyspraxia/Developmental Co-ordination Disorder (DCD) (category developed from open-ended responses) | 11 | 3 |

### Carers, parents and supporters of people with disabilities

Just over three quarters of the respondents who were carers, parents or supporters were women (n=123, 76%), 20% were men (n=33), and a small minority identified as another gender. Very few carers, parents and supporters were aged 18-24 (<5%), 56% were between 25 and 49 years old (n=91), 37% were aged 50-64 (n=60), and 8% were aged 65 to 79 (n=8). Three in ten carers, parents or supporters lived in a city (n=49, 30%), 21% lived in a large town (n=34), almost a quarter lived in a small town (n=41, 24%), and just over one fifth lived in a rural area (n=22, 36%). Over half of the carers reported supporting one disabled person (n=85, 53%), over one fifth reported supporting two disabled people (n=37, 23%), and 5% supported three to four disabled people (n=8). Fifteen percent reported supporting five or more disabled people (n=24) and this high figure likely indicates that some carers working in service provider organisations completed the questionnaire. Overall, 44% of these respondents (n=72) cared for a disabled child or children, while 41% cared for a disabled adult or adults (n=66) and 10% cared for both children and adults (n=16).

# 2.2 Analysis

Data collected throughout the course of the consultation consisted of:

* detailed notes from focus groups, interviews and consultation meetings,
* survey responses,
* written submissions and transcripts of video submissions,
* reports from ACE Communication and Inclusion Ireland.

Comments made by DPO representatives were identified at source to ensure their feedback could be emphasised in this report. Data were analysed by the NDA research team. No personal data were collected, and notes were recorded in such a way that individuals were not made identifiable.

Quantitative data from the survey were analysed through Statistical Package for the Social Sciences (SPSS) Version 29. All qualitative data (i.e., focus group and interview notes, written and video submissions, consultation meeting notes, and written responses to open-ended survey questions) were organised in NVivo (qualitative analysis software). A code book was developed to identify emerging challenges, barriers, solutions, and actions raised across the consultation. In total, over 3,500 pieces of information were coded in NVivo. Codes were grouped according to topic and themed as context, challenges, and actions and solutions. To ensure a rigorous ongoing analysis, the NDA consultation team met regularly to discuss how the experiences, views and ideas of all consultation participants and stakeholders were best represented in the report. People’s challenges as they experienced them and suggestions as they conceived them were the focus of this report to ensure that the voices of people with disabilities were accurately represented.

1. Survey findings on quality of life and disability awareness

One aim of the consultation survey was to identify the issues most important to disabled people’s quality of life in Ireland. Another aim was to explore how people with disabilities feel they are treated and how their disability is understood by people in their lives. Inclusion of survey questions on these topics was influenced by early consultation activities, in which participants argued strongly that the new National Disability Strategy should align with the quality-of-life priorities of disabled people and that the strategy must address negative experiences stemming from poor disability awareness and competence of others.

# 3.1 Issues important to quality of life

Survey respondents were asked to rate the importance of each of a range of issues to their current quality of life on a five-point scale from ‘not important at all’ to ‘very important’.

Figure 1 shows the percentage of survey respondents who rated each issue as very or quite important, as neutral, or as of no or low importance to their quality of life right now.[[12]](#footnote-13) The three issues rated as important by the highest proportion of respondents were getting health or social care services and supports, having enough money to cover the extra costs related to their disability, and being able to get and use public or private transportation easily (each rated as very/quite important by 90-93% of respondents). Eighty-five percent of respondents rated being able to access and use public buildings, streets, and parks as important to their quality of life, and 84% rated being able to go to cultural events and places for fun and entertainment as important. Further, 83% rated getting information communicated to them in a way they understand as being very/quite important to their quality of life. Equal proportions of respondents reported that support to live more independently and getting technology, aids or tools that can support them were important to their current quality of life (82% in each case). Over three quarters of respondents rated getting to do sports or activities they like or want to do as important (79%), and 71% rated getting a job or into training as important to their quality of life. The three areas rated as important by the lowest numbers of respondents (but still rated as very/quite important by a majority of people) were getting accessible housing (70%), getting into education (68%), and getting a chance to have a meaningful relationship (56%).

Figure 1. Importance of issues to disabled survey respondents’ quality of life

**This figure is a bar chart showing the percentage of survey respondents who rated each issue as very or quite important, as neutral, and as not important or of low importance to their quality of life right now. 
93% of respondents rated having enough money to cover the extra costs relating to their disability as very or quite important, 4% rated this as neutral, and 3% rated this as of no or low importance.
92% of respondents rated getting health or social care services and supports as very or quite important, 5% rated this as neutral, and 4% rated this as of no or low importance.
90% of respondents rated being able to get and use public or private transportation easily as very or quite important, 5% rated this as neutral, and 5% rated this as of no or low importance.
85% of respondents rated being able to access and use public buildings, streets, and parks as very or quite important, 10% rated this as neutral, and 4% rated this as of no or low importance.
84% of respondents rated being able to go to cultural events and places for fun and entertainment as very or quite important, 11% rated this as neutral, and 6% rated this as of no or low importance.
82% of respondents rated getting support to live more independently as very or quite important, 8% rated this as neutral, and 9% rated this as of no or low importance.
82% of respondents rated getting information communicated to them in a way they can understand as very or quite important, 12% rated this as neutral, and 6% rated this as of no or low importance.
82% of respondents rated getting technology, aids or tools that can support them as very or quite important, 12% rated this as neutral, and 6% rated this as of no or low importance.
79% of respondents rated getting to do sports or activities they like or want to do as very or quite important, 14% rated this as neutral, and 7% rated this as of no or low importance.
70% of respondents rated getting accessible housing as very or quite important, 14% rated this as neutral, and 17% rated this as of no or low importance.
68% of respondents rated getting a job or getting into training as very or quite important, 17% rated this as neutral, and 15% rated this as of no or low importance.
68% of respondents rated getting into education as very or quite important, 17% rated this as neutral, and 15% rated this as of no or low importance.
56% of respondents rated getting a chance to have a meaningful romantic relationship as very or quite important, 21% rated this as neutral, and 23% rated this as of no or low importance.
**

# 3.2 Disability awareness and attitudes of others

## 3.2.1 Awareness of disability by others

Survey respondents with a disability were asked whether they felt certain people in their lives had enough awareness of their disability. Figure 2 shows that the groups most likely to be reported as having enough disability awareness were family (53%) and friends (40%). The groups most likely to be reported as not having enough awareness were the general public (84%) and people providing everyday services, such as shop assistants (81%).

Of concern is that 62% of disabled survey respondents felt that health and social care staff were not aware enough of their disability, and 79% felt that people providing other public services, such as social protection, local authority and public transport staff did not have enough awareness of their disability. Over half of respondents felt employers did not have enough awareness of their disability (52%), and 68% felt acquaintances, peers, work colleagues, and neighbours were not aware enough.

Figure 2. Perceived adequacy of disability awareness of different groups in society

This figure shows a bar chart indicating survey respondents’ views on whether people in their lives have enough awareness of their disability.
53% said their family had enough awareness of their disability, 41% said they did not, and 7% did not know.
40% said their friends had enough awareness of their disability, 46% said they did not, and 14% did not know.

29% said health and social care staff had enough awareness of their disability, 62% said they did not, and 10% did not know.
15% said their acquaintances, peers, work colleagues and neighbours had enough awareness of their disability, 61% said they did not, and 17% did not know.
12% of respondents said their employers had enough awareness of their disability, 52% said they did not, and 35% did not know.
7% said people providing other public services, such as social protection, had enough awareness of their disability, 72% said they did not, and 13% did not know.
6% said that people providing everyday services, such as shop assistants, had enough awareness of their disability, 81% said they did not, and 13% did not know.
4% of disabled respondents said the general public had enough awareness of their disability, 84% said they did not, and 12% did not know.

## 3.2.2 Treatment by others

Disabled survey respondents were asked if they felt they are treated any differently by various people because of their disability. Table 2 shows the percentages of respondents who reported they were treated more negatively than others, the same as others, or more positively than others because of their disability.

Table 2 indicates that people providing public services such as social protection, local authority, and public transport staff (45%) and the general public (43%) were most likely to be identified as treating people negatively because of their disability. While family and friends were least likely to be identified as treating people negatively because of their disability, these percentages were still notable, with 26% of respondents feeling their family treated them more negatively and 18% feeling friends treated them more negatively because of their disability. Friends (54%) and family (44%) were the two groups most likely to be identified by respondents as treating them the same as others. Similarly, family was the group most likely to treat respondents positively because of their disability (19%), followed by friends (14%).

Table 2. Disabled people’s treatment by others as a result of their disability

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | Treated more negatively  % | Treated the same  % | Treated more positively  % | Not relevant/ don’t know  % |
| People providing other public services such as social protection, local authority, and public transport staff | 45 | 25 | 7 | 24 |
| General public | 43 | 31 | 7 | 19 |
| People providing everyday services, such as shop assistants etc | 38 | 31 | 10 | 21 |
| Health and social care staff | 37 | 37 | 14 | 13 |
| Acquaintances, peers, work colleagues, neighbours | 36 | 29 | 10 | 25 |
| Employers | 35 | 20 | 4 | 40 |
| Family | 26 | 44 | 19 | 11 |
| Friends | 18 | 54 | 14 | 15 |

1. Feedback on strategy development, implementation and monitoring

Attendees of the online and in-person consultation meeting events in Dublin, Cork and Galway were asked several direct questions about how ongoing engagement with disabled people and their representative organisations could best be achieved throughout the lifetime of the strategy. These included questions about effective forms of engagement with people with disabilities and with seldom-heard-from and diverse groups in particular. Across other consultation activities, participants also provided unprompted input and recommendations on this topic. Consultation participants also offered practical suggestions on how strategy actions should be drafted and prioritised, how implementation efforts should be coordinated, and how monitoring and oversight structures should function. All responses were grouped into themes and are discussed below.

# 4.1 Stakeholder engagement in strategy development, implementation, and monitoring

## 4.1.1 Putting disabled people and lived experience at the centre

Consultation participants emphasised the need to ensure the inclusion and meaningful participation of people with disabilities and lived experience in any engagement structure, reflecting the principle of ‘Nothing About Us, Without Us’. One consultation participant stated:

‘Having active representatives would be very important in this role. To have someone who experiences various barriers in their communities first hand would be incredible in speaking out and highlighting issues for change.’

Disabled Persons’ Organisations (DPOs) stated that the UNCRPD requires more than just consultation – disabled people must be actively involved in the development and implementation of policies and decision-making. There was also support, particularly from DPOs, for a stakeholder engagement structure that prioritises the co-creation of solutions with people with disabilities, rather than a forum to solely raise problems and issues.

## 4.1.2 Central involvement of Disabled Persons’ Organisations

DPOs sought central involvement in any engagement or monitoring structure and cross-departmental representation, drawing attention to Articles 4(3) and 33 of the UNCRPD and the requirement to prioritise their views. DPOs underlined that representative organisations, not service providers, should be driving policy and that DPOs should be adequately resourced and supported to ensure meaningful participation and consultation. There were also calls for an enhanced profile for DPOs in society, stronger partnerships between DPOs and government departments, and the creation of a publicly accessible list or register of DPOs. One DPO stated that consultation should be ‘deep rather than wide’, while another DPO representative stated:

‘The centring of DPOs is important. In the diagram of the [strategy’s] proposed monitoring structure, DPOs are floating off to the side. It is therefore not clear how and where DPOs plug in.’

## 4.1.3 Engagement between Government departments and disabled people

Consultation participants emphasised the importance of regular, genuine, and transparent engagement between government departments and disabled people. Identified challenges related to this included high levels of mobility within the civil service, difficulties identifying relevant officials and points of contact, the sense that there is a desire by officials to pass responsibility to other departments or agencies, and prior experience of unhelpful attitudes. For example, one consultation participant explained:

‘When engaging with a department or service, you can be at the mercy of the attitudes of the individual who are dealing with.’

Common suggestions to address these issues included the provision of disability inclusion training, and training on the UNCRPD and other relevant statutory obligations, including the Irish Sign Language Act 2017. Other recommendations related to increasing the number of disabled people working in the public and civil service, accommodating different communication preferences, as well as civil servants visiting organisations and hearing from people with lived experience and those working on the ground.

## 4.1.4 Accessible information and communication

Accessible information and communication regarding engagement and consultation opportunities were considered crucial by participants, as well as regular progress updates via newsletters or ebulletins. They said, for example: ‘Accessible information is key, and we are not doing it well in Ireland.’ It was stressed that information and consultation outputs should be available and communicated in accessible, person-centred, and diverse formats, including Irish Sign Language (ISL), plain English and Easy Read documents and visual communications.

## 4.1.5 Form and structure of engagement

There was support for genuine, ongoing dialogue and engagement with people with disabilities throughout the lifetime of the strategy. DPOs highlighted the need for formalised engagement, with clear terms of reference agreed from the outset and a transparent selection process for membership of any monitoring structure. One DPO favoured limits to membership of any engagement and monitoring structure. In addition, a few consultation participants supported the establishment of a reference group to monitor implementation of the strategy, with the model of the Reference Group for the Sharing the Vision National Implementation Monitoring Committee identified as good practice.

The proposed approach of creating sectoral oversight groups for each of the five key pillars of the strategy was broadly welcomed, though some consultation participants considered it somewhat complicated. It was also noted that any engagement structure should be accessible and rights-based. They said the structure should ‘have teeth’ and the necessary expertise and cross-departmental buy-in at senior levels. There was also some support for a participatory annual meeting or forum to assess progress achieved in the implementation of the strategy.

Feedback on the Disability Stakeholders Group (DSG)[[13]](#footnote-14) was very limited and mixed. For example, while one consultation participant labelled the DSG monitoring of the previous National Disability Inclusion Strategy (NDIS) ‘a failure’, another praised its diverse and representative composition, though added that it had limited terms of reference. In one written submission, it was outlined that the DSG was perceived as functioning proficiently as an expert advisory panel but ultimately lacking in power to drive actual implementation. The DSG offered guidance on implementation which departments responsible for implementing actions were not obliged to follow.

It was also noted that children with disabilities were not included in the monitoring of the previous NDIS, and it was argued that this should be rectified in the successor strategy.

## 4.1.6 Supports for engagement

Consultation participants underscored the importance of supporting and building the capacity of people with disabilities to engage and participate in consultations and decision-making processes, including seldom-heard-from groups. Challenges to effective engagement identified by disabled people included financial cost and barriers connected to a lack of transport, broadband, and personal assistance.

Accessibility measures and accommodations were considered crucial and should be in place for the duration of a consultation, with some consultation participants highlighting the lack of availability of Irish Sign Language (ISL) interpreters at arrival or registration for consultation events as a barrier. Well-resourced advocacy services were also identified as a particularly important form of support, including for seldom-heard-from groups, with one consultation participant explaining: ‘There is no funding for advocacy. There needs to be funding for advocacy to support people to participate.’ There was also a suggestion to pay disabled people to participate in consultations.

## 4.1.7 Flexible and local engagement

Consultation participants voiced support for flexible, proactive, grassroots approaches to engagement, including the organisation of online, hybrid, and in-person meetings at convenient times and engagement with seldom-heard-from groups in their communities. There was a strong feeling of a disconnect between national strategies and realities on the ground, with calls for more involvement by local authorities and additional engagement opportunities for disabled people at local levels, particularly outside of Dublin:

‘In order to better meet the needs of the community, it’s crucial to increase the number of staff members who are dedicated to conducting public consultations. By going out into the communities and meeting people where they are, we can ensure a more inclusive and effective decision-making process.’

Participants suggested that information on engagement opportunities could be disseminated through informal channels, such as Facebook and WhatsApp groups, and by leveraging existing networks and relationships to reach seldom-heard-from groups, such as through day services, representative and umbrella organisations, DPOs, Citizen Information Centres, GPs, and pharmacies. However, it was also noted that smaller organisations and disabled people who are not linked into organisations or services cannot be excluded.

## 4.1.8 Meaningful engagement

Meaningful and honest engagement which builds trust with stakeholders was considered important, with one participant stating: ‘Whatever the structure, disabled people need to know that their voices are going to be heard.’ Consultation participants objected to tick-box, tokenistic engagement and leading questions during consultations, highlighting previous negative experiences engaging with government departments, ‘consultation fatigue’ and a lack of faith in the outcome of consultation processes. The importance of a ‘living’ strategy which can be updated to reflect emerging issues, of frank dialogue and of closing the ‘feedback loop’, by providing feedback to consultation participants, were deemed critical. One consultation participant suggested a change in language from ‘consultation’ to ‘participation’.

## 4.1.9 Timely engagement

There were strong views expressed that engagement with people with disabilities should happen from the very outset of strategy development, with some noting that consultations often take place too late in the decision-making process. One participant stated:

‘Include the ones with a lived narrative in the decision-making process, from top to bottom, this includes during the initial stakeholder process.’

Consultation participants underlined the importance of sufficient advance notice for consultation and engagement opportunities and of the circulation of materials in advance. There was some criticism for the short lead-in time for this consultation, with some organisations reporting that they did not have sufficient time to consult with disabled people and their members. DPOs felt strongly that disabled people should be given the time and space to contribute according to their needs.

# 4.2 Strategy development

## 4.2.1 Vision

Attendees of the series of consultation meeting events were asked to provide input on what the vision of the new National Disability Strategy should be. Participants were invited to reflect on examples of vision statements from national disability strategies in Scotland, New Zealand, Australia, and Sweden (see Box 1) and consider which elements might be suitable in an Irish context.

Box 1: International examples of vision statements from national disability strategies

Box states:
Scotland: Disabled people should have freedom, dignity, choice and control over their lives. We want to remove the barriers that stop people from enjoying equal access. 
New Zealand is a non-disabling society - a place where disabled people have an equal opportunity to achieve their goals and aspirations, and all of New Zealand works together to make this happen.
Australia: The Strategy’s vision is for an inclusive Australian society that ensures people with disability can fulfil their potential, as equal members of the community.
Sweden: The vision is to achieve equitable living conditions and full participation in a diverse society for people with disabilities.Feedback on individual countries’ vision statements

There was a clear preference expressed by DPOs and others for vision statements that align with the social model of disability and that emphasise a collective responsibility to remove barriers and promote social inclusion. New Zealand and Scotland’s visions were particularly favoured for their emphasis on societal change over individual adaptation. There was a greater variety of views and critiques on the Australian and Scotland perspectives, reflecting the nuances of participant preferences and the complexities involved in formulating a vision statement for a national disability strategy on which there is consensus.

#### Scotland example

The Scottish vision statement was well regarded for its clear commitment to removing barriers and to promoting individual autonomy, dignity, and choice. The close alignment of the statement to the social model of disability was viewed as a positive by DPOs and others. Participants were generally in favour of the emphasis on the provision of equal access for disabled people.

However, a criticism by many, including DPOs, of the word ‘should’ in the Scotland vision pointed to a preference for stronger, more definitive language that reflects a commitment rather than a conditional intention.

#### New Zealand example

The New Zealand vision was praised by DPOs and others for its inclusiveness and its emphasis on collective responsibility. Participants appreciated the statement’s encouragement for all New Zealand to be involved in removing barriers for disabled people. The vision’s broad appeal and the notion of ‘working together’ were seen as strengths.

However, there were also some criticisms of the vision as being somewhat vague and lacking in concrete aspirations. Some consultation participants felt that the language of ‘non-disabling society’ was not entirely clear or inspiring enough to drive meaningful action. However, others, including DPO representatives, liked that this language aligned with the social model of disability. The concern was raised by a DPO that ‘equality of opportunity’ as included in the New Zealand vision is insufficient and that the focus on ‘equity’ in the Sweden example is more appropriate.

#### Australian example

Participants expressed some reservations about the Australian vision statement. The language used was perceived as lacking specificity and ambition, with a critique that it did not provide a clear, actionable path forward. One participant, for example, criticised the vision for being ‘wishy washy’. The phrase in the Australian vision statement about ‘people reaching their full potential’ was welcomed by a minority of participants but was more often singled out for criticism. For example, this language was criticised by one DPO representative as ‘othering’ and reflective of a power imbalance. The phrase was also described as being ‘very civil service’ and indicative of a passive approach that might not adequately empower individuals or drive systemic change.

However, there was appreciation expressed for the aspect of the Australian version that emphasised disabled people as equal members of the community. This element was seen as a positive inclusion, suggesting a desire for a vision that explicitly acknowledges and fosters the full participation and integration of disabled people within society.

#### Sweden example

The Swedish vision was well regarded for its straightforwardness and for its emphasis on equitable living conditions, which was viewed positively by several participants. This aspect resonated because it indicated a focus on creating tangible, equitable outcomes for disabled people and emphasised the need for systemic change to achieve these conditions.

Despite this, there was some negative reaction to the word ‘diversity’ in the Swedish example, with a concern that the vision should not become mired in broader concepts of diversity and inclusion but rather retain a clear focus on the needs of disabled people.

### Key messages for Ireland’s vision statement

Across the various country examples, participants criticised any use of passive or conditional language in the vision statements, advocating for definitive and action-oriented terms. They emphasised that the vision should not rely on what some felt were ‘buzzwords’ like ‘inclusion’ and ‘diversity’. There was a sense that these terms can be used as a ‘catch-all’ without any clarity as to what they translate to in reality, and that they are used so often they may have lost some of their original meaning and power. The importance of clear, plain language was raised repeatedly, to ensure accessibility, prevent misinterpretation, and rally broad support for the strategy.

A clear preference for the incorporation of equity, a social model orientation, and a rights-based approach was expressed by many consultation participants. The feedback reflected a desire for a vision that encompasses dignity, autonomy, non-discrimination, full participation, and equality. Consultation participants highlighted the need for the vision to be inclusive of all members of society, not just disabled individuals, promoting a universal approach to accessibility and participation.

### Other suggestions for Ireland’s vision statement

While the above summary reflects sentiments raised repeatedly over multiple consultation sessions, the following suggestions were raised less frequently but may still warrant consideration:

* A small number of participants recommended that there be explicit reference to the UNCRPD in the vision statement, e.g., including the language ‘in accordance with the UNCRPD’ or that the vision statement borrow language directly from the Convention;
* One participant raised the issue that there is no all-island approach to disability and that it might be necessary to specify that the vision relates to the Republic of Ireland;
* Using the language of ‘every disabled person’ rather than ‘disabled people’ was agreed on in one group discussion as preferable language for Ireland’s vision statement;
* A small minority of participants felt that the words ‘disability’ or ‘disabled’ should not appear at all in Ireland’s vision statement;
* One DPO representative raised the issue that some DPO members do not identify or wish to be identified as disabled and, in this context, treating people equally and a mainstreaming approach are key;
* It was discussed in one group that there should not necessarily be a vision statement in the strategy, only tangible, achievable, and measurable objectives. In another group, it was suggested that ‘vision’ is the wrong word; the strategy should be making a ‘commitment’;
* One group of consultation participants developed a wording of a vision statement on which they all agreed: ‘Ireland aims to be an enabling society. Our vision is to achieve equitable living conditions and full participation of disabled people as equal members of our community’; and
* One group suggested that the international visions should be shared directly with DPOs who could give their perspectives on them and/or could draft wording for the vision statement for Ireland.

## 4.2.2 Values

Attendees of the in-person and online consultation meeting events were also asked what values they believed should underpin the new strategy. The responses provided are grouped together below, reflecting similar or linked values.

### Respect and dignity

Respect and dignity were identified as key values. It was felt that the strategy should be centred on upholding the dignity and respect of people with disabilities and those who support them. A DPO felt this could be achieved by fostering a culture of equality, which values disabled people’s potential.

### Empowerment and social justice

Collective empowerment was felt to be a key tenet of the strategy, especially by DPOs. Empowerment was seen as a useful concept because it necessitates a shift away from viewing people with disabilities as recipients of care or charity, to individuals with goals and aspirations. There was also an understanding that the wider social justice movement must reflect the increasingly diverse population within Ireland.

### Collaboration

Collaboration was identified as a key value for the strategy. Participants were keen to have opportunities for meaningful engagement and participation throughout the process, from co-production to assessment and implementation. DPOs especially identified the need for active listening within safe spaces, to build trust and avoid tokenism.

### Innovation

It was recognised that there was scope to ‘do things differently’ and improve on the previous strategy. DPOs highlighted the need for risk-taking. Open-mindedness was seen as a key value for the strategy. Participants felt strongly that risk was required to make progress (i.e., ‘tearing up the rule book.’)

### Person-centred, holistic approach

Participants felt strongly that the new strategy must be a person-centred one. This would include designing holistic, mainstream services that can be accessed by people with disabilities alongside other family members at a local level. Participants felt that there was value in focusing on the talent of individuals and building supports around them to ensure their needs are met.

### Accountability

It was argued that accountability should be a key underpinning of the strategy. DPOs recognised that co-creation of plans would result in less finger pointing. Working together to create a plan means that if it fails, blame can be shared. It was felt that the value of the strategy must extend beyond words to actions, with cross-departmental communication and shared responsibility.

### Empathy and understanding

During the consultations, empathy and understanding were identified by participants as core values for the strategy. DPOs in particular emphasised that everyone has the potential to make mistakes and learn from them. They felt it could be beneficial to enter into open dialogue, seeking feedback and identifying problems, while recognising that no one has all the answers. There were requests to acknowledge failures and seek forgiveness when things do not work.

### Affirmation

Participants felt many disabled people do not get the recognition they deserve. It was deemed important to give disabled people a platform for advocacy, a strategy which affirms their identity and provides a sense of pride.

### Autonomy and choice

The concept of freedom featured prominently within the consultations. DPOs called for enhanced recognition of autonomy. They felt strongly that disabled people must be recognised as agents and supported to make decisions in their everyday lives, for example, where and with whom one lives.

### Sustainability and flexibility

During the consultations, there was a strong sense that the strategy must focus on the future, utilising long term planning to meet the changing needs of our society, especially children and older people. Participants were keenly aware of changing times and the need to embrace new technologies, for example, including blended meetings.

### Belonging and inclusion

The consultations identified a need to embrace difference within society; some suggested that we had moved beyond mere acceptance. There were mixed views on the topic of inclusion. It was acknowledged that overuse of certain buzzwords can create apathy. One participant suggested the term inclusion had been ‘hijacked’. Another suggested that the strategy should address integration, progression, and parity of experience with non-disabled people. It was emphasised that people with disabilities can thrive and be included in a community as long as the correct supports are put in place. Participants felt strongly that people with disabilities deserve to have a sense of purpose and be valued for their contribution to the community.

## 4.2.3 Principles

Consultation meeting attendees were also asked which principles should underpin the NDS. To guide the discussion, the principles from Article 3 of the UNCRPD were presented to the groups. Participants’ responses relating to each of the Article 3 principles are outlined below, followed by some additional comments from participants on possible underpinning principles.

### Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons

An emphasis on respect throughout the principles underpinning the NDS was encouraged. Participants recognized the importance of person-centred supports, including legal supports such as assisted decision-making. There was an understanding that a person’s ‘will and preference’ can be subject to change over time and that a person’s capacity may also evolve. One participant suggested that the phrase ‘independence of persons’ added nothing tangible to this principle, and others argued for context in regard to the term ‘independent’ – in that it should not mean ‘unsupported’.

### Non-discrimination

Non-discrimination was not believed to be an appropriate guiding principle by all participants, as some identified scope for positive discrimination in education and employment contexts.

### Full and effective participation and inclusion in society

Participants were keen to be a part of an inclusive society, indicating that this is an important principle to guide the National Disability Strategy. It was felt that the wording of this principle could be strengthened by explicit reference to key domains, such as economic, social, and cultural participation. This could be linked to UNCRPD articles such as independent living (Article 19), recreation and sport (Article 30), health (Article 25), and political participation (Article 29).

### Respect for difference and acceptance of disabled people as part of human diversity and humanity

Participants were keen that the strategy recognise intersectional issues, as experienced by disabled people based on race or ethnicity, including membership of the Traveller community. There was an understanding that people with disabilities are not a homogenous group, but unique individuals. As such, difference must be respected and persons with different types of disabilities must be treated equally. A DPO highlighted that ‘normal’ is still the default, with non-disabled people seen as superior in a culture in which worth is tied to ability and productivity.

### Equality of opportunity

Participants were keen to draw a distinction between formal equality and substantive equality or equity. It was felt that this principle could benefit from a clear, specified definition.

### Accessibility

Concerns were raised that this principle is too broad and/or vague. Participants felt it required a clear definition, with explicit reference to Universal Design. Participants, including DPOs, felt that there must be a commitment to design services and spaces with and for people with disabilities, to minimise the need for future alterations or retrofitting. Participants emphasised accessibility as an over-arching concept, not just relating to physical spaces, education, employment, or access to information, but to all of the above.

### Equality between men and women

Discussions surrounding this potential principle centred on the need for more inclusive wording, with calls for the strategy to target equality among all genders. Participants, including DPOs, flagged that the UNCRPD language excludes some disabled members of the LGBTQI+ community, including trans and non-binary people. Some participants called for this principle to be removed altogether in favour of broader focus on marginalised groups (see above) or a general reference to equality between people. One participant sought language to clarify the intersection of gender and children’s rights; that is, the rights of boys and girls with disabilities.

### Respect for the evolving capacities of disabled children and respect for the right of disabled children to preserve their identities

Consultation participants felt it was vital for this principle to be informed by Article 3 of the United Nations Convention on the Rights of the Child (UNCRC) and the ‘best interests of the child.’ This proposed principle was approved of by many, who highlighted the need for children with disabilities to receive additional supports under the Disability Act 2005 and the EPSEN Act 2004.

### Additional principles

In addition to considering the merits of the UNCRPD principles, consultation participants proposed the additional principles below to underpin the strategy.

#### ‘Nothing About Us, Without Us’

DPOs welcomed the idea of a principle which supported stronger consultation and the recognition of collective voices through representative organisations. This would be in accordance with UNCRPD Article 4 (3). Participants felt there was an opportunity to uphold the advocacy rights of people with disabilities, ensuring that they can speak and that the State will be obligated to listen. Participants also felt there should be content within the strategy on the subject of ‘Nothing About Us, Without Us’ – this feedback is discussed in detail in Chapter 5.

#### Accountability

There were calls for consistent, strong language in the strategy which holds the State to account, guarantees the rights of people with disabilities, and recognises their contribution to society.

### Other key messages

While discussing individual principles, consultation participants also flagged overall considerations for this section:

* ‘If it ain’t broke, don’t fix it.’ DPOs in particular felt that retaining the UNCRPD principles without modification in the National Disability Strategy would demonstrate a commitment to the UNCRPD framework as a whole;
* Some participants highlighted the potential to streamline the principles, feeling that certain broader principles covered others. The first three principles were noted as essential to the strategy, with the principle of participation deemed to ‘sum it up’;
* In their current form, the principles were seen as ‘wordy’ and complex by some participants, who felt they could benefit from clear, Plain English; and
* Participants identified the potential to link the principles with the Sustainable Development Goals or the Human Development Model of Disability.[[14]](#footnote-15)

## 4.2.4 Pillars

Attendees of the online and in-person consultation meeting events in Dublin, Cork and Galway were asked directly for their views about the five draft pillars of the strategy. The originally proposed five draft pillars were:

* employment and anti-poverty,
* transport and mobility,
* independent living in the community,
* wellbeing and social care services, and
* education and training.

Attendees’ views on these pillars are outlined below, alongside those expressed by other participants in the course of the consultation.

### Putting disabled people at the centre

There was a feeling that the initial draft pillars were designed around the structure of government departments rather than a disabled person’s life. Participants expressed a preference for placing the person with a disability at the centre of the pillars. It was argued that many of the pillars are interconnected and that a lifecycle approach to the strategy would be more appropriate:

‘A person’s life isn’t divided into government departments so the pillars should be more related to a person’s life rather than department structures.’

### Employment and anti-poverty

There was strong and consistent feedback from participants, particularly DPOs, that employment and anti-poverty should be separated, with some voicing support for the inclusion of ‘anti-poverty’ as a standalone pillar. The additional costs of having a disability, irrespective of employment status, were cited, with Indecon’s report on the ‘Cost of Disability in Ireland’ also referenced. Consultation participants argued that: ‘The answer to poverty isn't always employment’, and ‘Poverty needs to be on its own… You can still be in poverty if you are in employment or not.’

While the minority, some participants supported the explicit linking of employment and anti-poverty measures, asserting that there is a correlation between unemployment and poverty. For example, one consultation participant stated: ‘The lack of employment makes you poor, getting out of poverty is really difficult.’ The connection between employment status and social welfare payments was also raised, with unemployed people more likely to be in receipt of social welfare benefits to ensure basic financial support. One consultation participant favoured altering the wording of this pillar to ‘pathways to employment’ to cover transition points, while another suggested changing it to ‘Financial independence/security’.

### Education and training

There was some support for merging the pillars on education, training and employment, given the links and importance of transitions between these areas.

### Independent living in the community

There was significant confusion and uncertainty as to what the ‘independent living in the community’ pillar would encompass, with some noting that this pillar overlaps and cross-cuts with other pillars. Participants felt that this pillar should be clear about the need to ‘support’ independent living and supporting people to exercise choice, autonomy and control rather than simply living alone.

Another question and concern regularly raised by participants under this pillar related to the absence of an explicit reference to ‘housing’, which was identified as an integral component of independent living in the community. There was support for the addition of ‘housing’ to this pillar.

### Wellbeing and social care services

There were concerns regarding the wording of this pillar, particularly the inclusion of the word ‘care’. DPOs felt that this wording was paternalistic and connected to the medical model of disability, with some preferring a reference to ‘social supports’ rather than ‘social care’. There were also questions about the scope of services included within ‘social care’, including whether mainstream health services may be inadvertently omitted from this pillar. One participant argued: ‘[It] can imply that disabled people need to be ‘cared for’ rather than recognising their right to autonomy and choice.’

There were also concerns expressed by consultation participants regarding the omission of an explicit reference to ‘health’ in this pillar, with many supporting its inclusion. Participants questioned if health, including mental health, would fall within the scope of this pillar. Furthermore, there were views expressed that ‘wellbeing’ is too vague a term and more of a cross-cutting or overarching theme rather than a standalone one, with some questions also about the appropriateness of linking ‘health and wellbeing’ with ‘social care’.

### Other pillars, cross-cutting issues and concerns

Participants, especially DPOs, queried where cross-cutting issues and themes would sit within the draft pillars. Those specifically mentioned included accessibility, communication, disability equality or awareness training, human rights and Universal Design.

There were very few suggestions for introducing new pillars. However, proposals received from DPOs included:

* accessible communication (it was also asserted that if accessible communication is not included as a standalone pillar, that it needs to be the primary cornerstone of all pillars and a responsibility for all public bodies, including those not allocated actions under the various pillars),
* arts and culture,
* sports and recreation.

Other suggestions included:

* attitudes, understanding and awareness,
* inclusivity and diversity,
* pillars reflecting high level themes such as decision-making and participation.

One submission stated that the initial pillars were broad and complex, while another considered that the five chosen themes: ‘assume that there is an established diagnosis and services pathway in place’.

## 4.2.5 Action planning

When discussing the development of actions for the next National Disability Strategy, the vast majority of consultation participants focused their contributions on the potential content of these actions. However, a handful of participants expressed views on the process of action planning. The main theme of this feedback, received from DPOs and others, was that the next strategy should feature fewer actions than its predecessor, the National Disability Inclusion Strategy, which was perceived as ‘overly ambitious’ and difficult to implement. One survey respondent, for example, wrote: ‘Cut down on actions. It’s alright having actions, it’s the implementation of the actions that’s very important.’ Another wrote: ‘5 or 6 themes through the life course of disabled people should be identified and then a number of key strategic actions should be clearly identified under each theme.’

Just one respondent dissented from this majority view, arguing for a longer list of actions to be included in the strategy: ‘Do publish the long list and a plan of implementation... That way people will be aware of the longer commitment needed to get all items over the line.’

Other suggestions were that actions should be ‘concrete’, and ‘SMART - Specific, Measurable, Achievable, Realistic’ or SMARTIE (also inclusive and equitable), that there be timelines associated with any included actions, and that commitments to deliver be made by those tasked with implementing each action.

### Need for alignment with other strategies and policies

Several consultation participants emphasised the importance of aligning the National Disability Strategy with other relevant strategies and policies, both with those that have already been published and those in development. Participants described examples where previous strategies had not complemented one another and how this had led to challenges.

Throughout the consultation, participants named specific strategies or plans that should be considered when developing the National Disability Strategy. These include Sharing the Vision, Young Ireland, the National Positive Ageing Strategy, the National Dementia Strategy, the National Carers’ Strategy, the National Housing Strategy for Disabled People, and the SDG Implementation Plan. The importance of alignment with the UNCRC and not just the UNCRPD was raised.

## 4.2.6 Prioritisation

Survey respondents were asked to provide suggestions on how decisions about what to focus on in the strategy could be made. Overall, 53 respondents provided input on how prioritisation should be undertaken. Themes in the responses are presented below in order from most to least frequent.

### Ensuring inclusive and participatory decision-making

By far the most common response among respondents was that prioritisation should happen in collaboration with stakeholders. A small number of responses called for the involvement of the broader public in prioritisation (via referenda, citizens’ assemblies, or polls). Most responses on this theme indicated that suitably qualified non-disabled people (carers, family members, service providers, allies) should have a say in prioritisation. The consensus view was that any prioritisation should be primarily driven by those with lived experience of disability. Keeping the voices of disabled people at the forefront was deemed by many respondents as key to ensuring that the strategy reflects real needs and preferences. One survey respondent argued that prioritisation should be based on input from DPOs: ‘Focus on what DPOs say’.

Some respondents felt that the results of the initial public consultation should be used to prioritise actions for inclusion in the strategy, for example by identifying the issues raised most frequently and prioritising those for action: ‘Use this survey to figure out the amount of people who are affected by different issues and use the most numbers in each area to put in order of importance’ and ‘Whatever comes up most in the responses needs to be dealt with first.’

Others felt that once actions had been drafted for the strategy based on the initial consultation findings, there should then be a further consultation phase to prioritise which actions are included. It was suggested that this be achieved through activities such as polling or via input from committees or groups established for this purpose. For example: ‘Compile the most frequently occurring themes and open a public consultation to rate the most important’.

A small number of respondents emphasised the importance of intersectionality and ensuring diverse inputs into the process of prioritisation: ‘Ask and prioritise the views and lived experience of disabled people, including children, young people, women and other multiple diverse backgrounds’ and ‘The experts on disability in Ireland are those with disabilities themselves. It is important in these consultations that the intersecting identities of people with disabilities is considered and represented.’

What emerged strongly from the responses is that respondents did not want decisions around prioritisation to be made by government employees in isolation and that they must not be ‘politically driven’. For example, one survey respondent wrote that policy makers must determine: ‘What is most important to those who have a disability and not just decide upon themselves.’

### Prioritise actions that improve quality of life

Several respondents emphasised that actions should be prioritised based on the impact that they will have on disabled people’s quality of life. References were made to basing decisions on what makes disabled people’s lives easier, improves their well-being, makes them happier or improves their mental health, or supports them to live independent and fulfilled lives (see Chapter 3 for survey findings on issues important to disabled people’s quality of life).

### Identify priority groups

Some respondents advocated that the strategy should prioritise particular groups, such as those in greatest need or those who tend to be overlooked. Groups identified for priority action included children, adults cared for by elderly parents, blind people, and those living in rural areas. One respondent argued that people who had recently acquired a disability or received a diagnosis and were ‘recently traumatised’ should be prioritised, while others felt that those who had been disabled since birth and whose conditions were least likely to change should be prioritised in the new strategy.

### Address basic human needs

Several respondents said that addressing ‘basic human needs’ or the ‘most important issues’ must be the priority in the next National Disability Strategy. Where respondents specified what these fundamental issues or needs were, healthcare and housing were most frequently mentioned.

### Additional points raised

The sections above summarise the most common themes identified in survey responses on prioritisation when developing the new strategy. The following points were each made by fewer than five respondents, but may still warrant consideration:

* Ireland should look to other EU member states and see which actions they have prioritised in their national strategies;
* Actions necessary to meet Ireland’s obligations under the UNCRPD should be prioritised;
* Actions included in the National Disability Inclusion Strategy 2017-2022 that were not achieved in that strategy’s lifetime should be prioritised;
* A human well-being (capabilities) approach should be used in the strategy’s development;
* The strategy must be person-centred, respecting the personhood and dignity of all disabled people, and decisions around priorities should be made in that context;
* Roughly equal (and low) numbers of respondents argued that the strategy should prioritise actions with immediate impact, those with long-term impact, or argued for a mix of quick wins and bigger-ticket actions;
* Actions that affect the largest number of disabled people should be prioritised;
* Evidence-based actions should be prioritised (DPO contribution);
* The strategy should take care to avoid repetition or duplication;
* The strategy should seek to move beyond addressing urgent or crisis situations and towards planned, sustainable supports for people;
* Strategy prioritisation should be an evolving process, with the strategy being a dynamic plan that is responsive to emerging priorities and needs; and
* In the context of limited resources, some respondents cautioned against adopting a ‘one size fits all’ approach and against pitting different groups against one another when prioritising. For example: ‘Don’t put physical against intellectual, acquired against natal disabilities. Different need, different impacts’.

# 4.3 Strategy implementation, monitoring, oversight and accountability

## 4.3.1 Implementation

### Importance of focussing on implementation

Many consultation participants, including DPO representatives and others, emphasised the importance of a focus on implementation in the next strategy. Some participants spoke about how the challenges facing disabled people in Ireland are well known and that solutions to these have already been identified, including through research studies and previous consultations. However, there was a strong sense that previous recommendations have not been implemented: ‘We have solutions to the problems, but we are not implementing.’

Others expressed disappointment about the implementation of previous strategies and policy. One survey respondent, for example, wrote: ‘We are policy rich and implementation poor in this country. The people who need the supports/services get the crumbs off the table. The system is broken.’ In relation to the National Disability Inclusion Strategy (NDIS) 2017-2022 specifically, another survey respondent wrote:

‘Seems to me every time you set up a strategy, there's a review of the strategy, doesn't appear to be published for the public, then another one starts, and another one starts again. 125 actions within NDIS - where have those 125 things been implemented?’

In a written submission, one DPO quoted two of their members on this issue:

‘It’s easy to write long professional reports highlighting exclusion with all these definitions and legal formats that satisfy the professionals working on policy development at a desk, but what really matters is how I feel every day on the street and in society when I am trying to live my life with a debilitating disability.’

And

‘It’s time to call it as it is. All these reports and declarations are all fine, but the same thing is written in them for years and years. I acquired a brain injury in 2001 and I swear the very same recommendations are coming out every single year in shiny new book covers, but the issues and ‘what should be done’ statements inside are all the very exact same. We need action.’

There was a strong sense among participants of the need to ‘do things differently’ with this national strategy if it is to improve the lives of disabled people in Ireland.

Other consultation participants did not believe or trust that the National Disability Strategy would be implemented successfully. Examples of responses in this vein include: ‘I've no faith the findings will ever be implemented, and it will end up gathering dust like the EPSEN Act’, and ‘When I hear “National Disability Strategy” it sounds to me that the government are putting another plaster over the last plaster and the whole system is so infected it can’t move forward!’ A lack of trust was expressed, with one participant calling for ‘Less hoodwinking and winking behind people's back.’

Some participants disagreed with having a new strategy, or argued that that it would be either ineffective or harmful, e.g., ‘I don't think it will make any difference at all’, ‘Strategies that create more admin are counterproductive as they take time away and put more pressure on staff’ and ‘I completely disagree with this strategy’.

### Importance of a whole-of-government approach

Many consultation participants, including DPO representatives and others, expressed the need for successful cross-government collaboration in delivering the next National Disability Strategy. Several respondents perceived a lack of such cooperation in the past and spoke about departmental ‘silos’ and a ‘lack of joined-up thinking’. It was noted that disabled people are concerned about issues that span the remits of multiple government departments, and that a joined-up approach is essential. In a written submission, one organisation wrote:

‘Our examples vividly underscore the intricate interactions individuals with disabilities have with various government departments, underscoring the necessity for a holistic strategy that transcends traditional departmental boundaries. Whether it's accessing education, employment, or social services, the journey of individuals with disabilities traverses multiple sectors, necessitating robust support mechanisms that seamlessly integrate across governmental domains.’

Several respondents argued that the Department of the Taoiseach was the most appropriate coordinator of the necessary whole-of-government approach to implementation of national disability policy. For example:

‘Implementation is a complex project that requires effective cross-departmental work and a whole of government approach. The Department of the Taoiseach should take on the defined role outlined for it in the UN CRPD. Article 33 lays out an implementation and monitoring framework - consisting of a focal point, coordination mechanism, and monitoring body. The Government has named the focal point (DCEDIY) and the monitoring body (IHREC (Irish Human Rights and Equality Commission)) but has never named a coordination mechanism. The Department of the Taoiseach should perform this function, to ensure that action across government is coordinated at a senior level and works towards full implementation. Meaningful and effective cross-Departmental work is essential for UN CRPD implementation and has been lacking thus far – each Department has a role to play.’

One survey respondent advocated for devolved leadership on disability matters across government, rather than disability being the primary responsibility of one Minister of State. Others emphasised that funding streams for the strategy and for disability services more broadly should come from all departments, and not just the DCEDIY.

Where previous strategies have attempted to take a whole-of-government approach, this has not been perceived as successful. As one DPO representative put it: ‘The whole of government approach seems like box ticking, because it is not working’.

### Need for adequate resources

Consultation participants raised the importance of properly resourcing the implementation of the strategy if it is to meet its objectives. Time, staff, and money were the resources most frequently mentioned. It was recommended that the resources required to implement strategy actions be calculated and ringfenced prior to implementation: ‘A stocktake on the required resources, tools, and timelines to achieve the NDS is a prerequisite to implementation.’

Participants argued that if the strategy is truly a governmental priority, commitment to its implementation should be demonstrated by appropriate investment. For example:

‘We need this strategy to really work for us by being a living working document that has more than good will. This strategy needs a commitment from the government to resource it, invest in people with disabilities for there to be a meaningful outcome.’

It was argued that the Department of Public Expenditure, NDP Delivery and Reform must be fully engaged in strategy development from the outset to ensure adequate funding is available across the lifetime of the strategy. Participants spoke of the need for increased funding for both mainstreaming and specialist disability services. Commitments to provide multi-annual funding were called for.

## 4.3.2 Monitoring, oversight and accountability

Only a small number of focus group participants and survey respondents referred specifically to monitoring, oversight and accountability in their contributions; however, these issues were raised strongly and consistently across the written submissions received.

### Need for appropriate targets

It was repeatedly recommended that there be specific, measurable targets in the strategy and that progress towards these be regularly measured and reported. A lack of measurable targets was seen as a weakness of the National Disability Inclusion Strategy. It was emphasised that it is crucial that any targets be timebound and that there be clear accountability across government where targets are not achieved on time. One participant wrote:

‘Targeted measures and accountable evaluation processes will enable transparent identifiable successes and shortcomings of the strategy. It will be clear what is working well, where improvements are needed and why.’

### Importance of data

It was recognised that having targets necessitates the availability of appropriate data to monitor progress towards these. Collecting data was described by several consultation participants as important for gauging progress towards the implementation of actions and to evaluating outcomes and impact. Identifying the relevant data was suggested as an important early priority for those developing the strategy. It was raised in one written submission that Article 31 of the UNCRPD asserts that State Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the Convention and to monitor its implementation. It was argued that ‘This should be an integral part of any new National Disability Strategy’.

### Importance of transparency and accountability

It was expressed by several participants that there had been a lack of accountability for delivering previous national strategies: ‘There are too many organisations... who pass the buck’. With respect to UNCRPD implementation, it was stated that there is ‘no clarity on where accountability for failure lies’. True accountability was described as crucial if the NDS is to be successful. Public accountability was deemed to be particularly important. Participants suggested that departments should have to regularly report on implementation progress to the Oireachtas. One participant wrote:

‘Another crucial step is maintaining the Oireachtas Disability Matters Committee. The Committee has been an important forum in raising the profile on disability issues and working towards accountability and transparency on disability policy in the Oireachtas.’

### Need for appropriate monitoring and oversight mechanisms

The need for efficient and appropriate oversight of the strategy was raised by multiple participants. Participants called for clear lines of responsibility and accountability. This was seen as an area of weakness of the NDIS. The importance of regular reviews of progress was raised, as well as the need for learning from monitoring and reviews to be fed back into the strategy’s implementation so that the strategy is a ‘live’ rather than a static plan. It was emphasised that the results of any reviews must be communicated widely. One participant suggested that there should be a national website created on which monthly progress updates are provided.

Reference was made to the need for meaningful monitoring structures for the NDS, with one consultation participant expressing that it is ‘demeaning’ for the quality of disabled people’s lives to be reduced to spreadsheets. One written submission contained the following:

‘…when strategies are being reviewed the untrained eye might think that much work has been done. Those who are living through the experience of disability will likely think otherwise. Reviews can be a tick box exercise which show superficial ways that the government is addressing issues.’

The link between the volume of actions in a strategy and the nature and extent of monitoring that can be undertaken was raised. It was recognised that only superficial monitoring could take place of the implementation of the NDIS, given its 135 actions and the type of monitoring and oversight structures instituted.

In a written submission, one DPO argued that an important learning from the monitoring of the NDIS was that there should be ‘a focus placed on processes rather than outcomes as a means to measure achievements.’ However, others felt that monitoring should be outcomes-focused rather than focusing solely on inputs or processes.

It was argued by several respondents, including DPOs, that disabled people must be centrally involved in monitoring outcomes:

‘We need to keep tracking things and keep an eye on progress, and it is important how that all gets shared and how we can use that communication to move forward and keep pushing.’

1. Proposed actions and solutions to address challenges faced by disabled people in Ireland

Across all consultation activities, participants were asked to provide their views about the challenges disabled people face in Ireland. They were also asked to propose actions and solutions to address these challenges that could be included in the National Disability Strategy. This chapter describes their feedback across seventeen main topics. Each section opens with a brief explanation of the topic context and a summary of the main reported challenges. Proposed actions and solutions are then outlined. Any points raised by representatives of Disabled Persons Organisations (DPOs) are identified throughout.

The sections vary in length, reflecting variation in the volume of feedback sought and received on different topics. For example, health and social care services was by far the most common topic raised. Other topics on which substantial input was received include ‘education and training’, ‘awareness, attitudes and discrimination’, ‘employment’, ‘financial independence and security’. Somewhat frequently raised topics included ‘accessibility’, ‘independent living’, ‘Nothing About Us Without Us’, and ‘housing’. Less frequently raised topics included ‘UNCRPD’, ‘culture, recreation, leisure and sport’, ‘disability legislation’, ‘data and research’, ‘justice’, ‘abuse and violence’, 'climate justice’, and ‘international cooperation’.

# 5.1 ‘Nothing About Us, Without Us’

## 5.1.1 Context and challenges

Throughout the consultation, participants called for disabled people to have more control in the decisions that affect their lives. This includes, but goes beyond, their involvement in the development, monitoring and implementation of the National Disability Strategy as discussed in Chapter 4. Many participants drew on the slogan ‘Nothing About Us, Without Us’ to stress how disabled people, as the experts in their own lives, and their representative organisations, must be involved in decision-making processes before any laws and policies are made, changed, or implemented. There were calls for Irish policy makers to understand and incorporate this concept into all public communications efforts regarding disability rights. Representatives of DPOs particularly stressed the call for more advocacy, voice, representation, and decision-making powers.

### Underrepresented voices in decision-making processes

Consultation participants stressed that many people with disabilities feel they have been left out of decision-making processes that affect every aspect of their lives. In particular, advocacy organisations for people with intellectual disabilities raised the concern that those who have high support needs are often underrepresented in consultations and decisions about policy. For example, one submission included the following statement:

‘Consequently, there is a risk that their unique perspective and voice is not accounted for in strategic planning. Important to note the fact that people with higher support needs access the vast majority of the budget spend in specialist disability services, it is absolutely critical that their voice is heard consistently, in ways that are meaningful and rights centred.’

Participants with intellectual disabilities also called for more advocacy and self-advocacy supports. Participants with Down Syndrome, for example, said that advocacy groups in their organisations ‘are too small scale’ and argued that all people with Down Syndrome should have a voice. Others called for more supports for advocacy because, as one participant said, ‘we are very much at the mercy of the service providers’.

Other participants highlighted the historic failure to actively involve children with disabilities in consultations informing many existing laws, policies, and programmes, and how in the current representative landscape in Ireland, there is no DPO for children with disabilities.

### Role of DPOs

Across the consultation, DPO representatives named several instances where DPOs felt they were not sufficiently engaged as part of decision-making processes, such as in the Department of Social Protection’s Green Paper on Disability Reform consultation. It was asserted that a DPO-produced paper on education did not receive feedback from the Department of Education, and DPOs expressed dissatisfaction that non-DPOs are ‘taking up their seats’ on accessibility committees; it was also asserted that DPOs are not prioritised in the European Accessibility Act.

From experiences like these, DPO representatives and many other consultation participants stressed the importance of accepting, centralising, and prioritising the views of DPOs in decision-making processes. One DPO representative, for example, stressed how the ‘collective voices’ of DPOs needs to be distinguished from the views of individual disabled people, families, and disability service providers. Articles in the UNCRPD (e.g., 4.3 and 33.3) were often used to argue for greater involvement of disabled people and DPOs in decision-making processes. For example:

‘The Government has ratified the UN Convention on the Rights of People with Disabilities but doesn't appear to have taken much action to prioritise the rights of people with disabilities through disabled persons' representative organisations (DPROs). It seems that input from service providers continues to be treated more seriously than input from DPROs’.

DPOs, however, also raised capacity challenges, such as limited funding and resourcing to enable their involvement, to ensure their effective functioning as representative organisations, and to empower themselves to carry out their responsibilities. For example, one DPO submission reported that without core funding, DPOs are struggling to pay staff, retain talent, and employ/include underrepresented disabled people (e.g., those with high support needs). Without adequate resourcing, they believed the ‘status quo’ of making decisions about disabled people, without disabled people, will remain intact.

### Role of non-DPO NGOs

Some participants from disability advocacy organisations argued that because not all disabled people can self-advocate and/or do not have access to appropriately resourced DPOs to promote their interests, there is an important and essential role to be played by non-DPO non-governmental organisations (NGOs) in advocating on their behalf. For example, some written submissions argued that UNCRPD General Comment No. 7 is clear in acknowledging the role of supporters and/or family members when and if that role focuses on the autonomy and active participation of their relatives with an intellectual disability, dementia and/or disabled children, and when these groups of disabled people want to be supported by their families as united networks or organisations. As a result, one written submission argued:

‘Government departments and bodies should therefore take heed of the wealth of knowledge and experience harnessed within NGOs – whether they be DPOs or civil society organisations – in drafting legislation and assembling plans.’

Another submission set out a detailed argument for how parent and family groups should be officially recognised as DPOs and be invited to participate and contribute equally with other DPOs towards the consultative processes in the drafting of policies, strategies and action plans concerning issues related to people with disabilities. They clarified that the role of parents, relatives and decision-making supporters in such organisations should be to assist and empower disabled people to have a voice and take full control of their own lives. Such organisations should actively work to promote, and use supported decision-making processes to respect and ensure the rights of disabled people to be consulted and to express their own views.

### Representation in politics and political life

There were calls for more people with disabilities in political life and more disabled politicians because, as one participant said, ‘I feel like politicians look down on us. They don’t take us seriously’. Participants highlighted that disability representation in politics in some other countries, such as the UK and Spain, is better than in Ireland. Some participants stressed that people with disabilities should be encouraged to vote and that communication and physical barriers (e.g., information, transport, voting stations) preventing people from voting need to be addressed. It was highlighted that UNCRPD Article 29 enshrines the right of people with disabilities to participate in political and public life.

## 5.1.2 Proposed actions and solutions

Consultation participants provided many suggestions for how challenges in this area could be addressed in the new National Disability Strategy. These suggestions are listed below and focussed largely on building DPO capacity, prioritising and distinguishing DPO perspectives from non-DPOs, and considering how other important stakeholders can also be acknowledged and included in decision-making.

### Building DPO capacity

* Provide adequate and multi-annual funding for DPOs;
* Provide appropriate targeted core institutional funding for advocacy DPOs commensurate with need (DPO contribution);
* Provide proper discretionary funding for DPOs in line with the government's obligations under the UNCRPD;
* Support DPOs to build capacity to get around infrastructural barriers, such as setting up a collective bank account and becoming a Company Limited by Guarantee (DPO contribution);
* Create a separate corporate category of DPOs which is in keeping with the criteria set out in UNCPRD General Comment No.7 (DPO contribution);
* Raise awareness among disabled people and their families about joining already-existing DPOs or to set up their own if there is none already representing their constituency. Discourage duplication of DPO work (DPO contribution); and
* Establish DPOs, in an appropriate way, for people with more significant support needs and for children with intellectual disabilities.

### Prioritising and distinguishing DPOs

* Develop a national policy and framework on the recognition and consultation of people with disabilities and their DPOs (DPO contribution);
* Include DPOs in the consultative process at the outset of any new policies being introduced in Ireland (DPO contribution);
* Ensure disability-proofing by DPOs of all policies, plans and legislation (DPO contribution);
* Create interdepartmental disability working groups which have input from DPOs as well as a dedicated disability focal person;
* Create a register of DPOs (DPO contribution);
* Reach out to and include local and grassroot self-advocacy groups representing various facets of disability in consultations and not just professional DPOs;
* Raise awareness among disability service providers of the need to be closely consulting and actively involving DPOs in their own advocacy work (DPO contribution);
* Allow DPOs to set the agenda for necessary retrofitting of ‘disablist’ designs and plans (DPO contribution); and
* Include DPOs immediately, in a meaningful way, in the National Development Plan and the Sustainable Development Goals (DPO contribution).

### Other actions

* Ensure all government departments have disability representation, with meaningful resources and authority;
* Include children with disabilities in decisions about child and disability-focused laws, policies, and programmes;
* Provide training and capacity-building to government departments and public bodies on designing and undertaking inclusive and accessible processes that ensure equal consultation and participation of children with disabilities;
* Recognise some parent and family groups as official DPOs; and
* Ensure transparency from government departments about how consultations impact their decision-making processes.

# 5.2 Awareness, attitudes, and discrimination

## 5.2.1 Context and challenges

Consultation participants discussed how barriers to an inclusive society for people with disabilities in Ireland stem both from institutional ableism[[15]](#footnote-16) and interpersonal discrimination. Disabled participants spoke of their experiences of prejudiced attitudes in their communities as well as discrimination experienced in their interactions with the State. Lack of due consideration of some disability types in policy, societal attitudes, stigma, and a lack of understanding of disability were repeatedly reported as having a profound negative impact on the well-being of disabled people.

### Ableism and stigma

Many consultation participants, including DPO representatives, reported that prejudice and discrimination towards disabled people are pervasive in Irish society. Disabled people were described as being treated as inferior, with the term 'second class citizens’ being used repeatedly (and ‘fourth class citizens’ in one instance). It was suggested that disabled people are treated better in other EU countries than in Ireland.

Persistent stigma and fear around disability were discussed, as well as the negative effects of this stigma on individuals. For example:

‘The societal stigma and lack of understanding surrounding diverse disabilities, especially invisible disabilities, have contributed to my feelings of abandonment and worthlessness. I am punished and excluded because of my disability because they do not understand it.’

In a focus group with members of the Traveller community, it was reported that there is much stigma surrounding disability among Travellers: ‘Within the community there is a lot of shame and stigma attached, whether you're a child, young person, or a parent. So, that needs to change.’

Disabled people described being bullied, harassed, or otherwise treated cruelly because of their disability. For example, one survey respondent wrote:

‘I hope people stop calling me ableist slurs. Though my disabilities aren't visible, some people can still tell that I'm different. It sickens me how people talk about my disabilities when I'm not in the room.’

Several consultation participants called for people with disabilities to be treated with kindness, respect, and dignity. In a video submission, one participant said:

‘I think all people with disabilities should be treated fairly and kindly. Stand up against cruelty. Because sometimes our world isn’t always kind. It is a dark and cruel place to live in.’

One DPO representative raised the issue of children experiencing bullying at school because of their disabilities and highlighted the negative effects of this treatment on children’s well-being.

Several participants spoke about the prevalence of paternalistic attitudes towards disabled people. Disabled people spoke about being treated like children and being perceived by others as incapable of having romantic relationships or of having children. They spoke of having others make decisions on their behalf and recounted experiences of being spoken down to, treated as though they do not understand things, and being ignored. This issue was raised by people with intellectual disabilities as being a particular problem for them. As an example, one participant with Down Syndrome was refused a taxi trip as she was unaccompanied. Her parent accompanied her to the taxi but was not taking the trip with her. The taxi driver said he would not take responsibility for a child, despite the person and her parent confirming that she was an adult (almost 30). Children and young people with intellectual disabilities also expressed frustration at being treated like younger children without capacity to understand or make decisions.

One DPO representative raised the issue of ‘internalised ableism’, which was described as ‘quietly pervasive’ in Ireland, with people often unaware of their biases. This participant went on to describe how disabled people can internalise ableist messages and stereotypes as a way of making non-disabled people ‘more comfortable’.

One survey respondent argued that denial or minimisation of the threat that COVID-19 still poses to the health of disabled and chronically ill people is ableist.

‘We have created an awful narrative that just because IC [immunocompromised] and people with disabilities are the ones most likely to die then its ok - 'normal' people don’t have to take any responsibility.’

This person called for ‘Recognition that we are living in a pandemic and that ignoring this while producing a new disability strategy is absolute ableism.’

### Lack of awareness and understanding

Some participants explained that prejudice and discrimination can arise from a lack of understanding around disability, and many consultation participants spoke about a lack of awareness and understanding among the general public. This echoes survey findings on disability as reported in Chapter 3. In particular, many consultation participants spoke of a lack of understanding about what were repeatedly termed ‘invisible disabilities’ and occasionally ‘hidden’ or ‘unseen’ disabilities. Examples cited of such disabilities included neurodivergence, mental health difficulties, disabilities acquired as a result of ageing (such as cognitive impairment) and learning differences such as dyslexia and dyscalculia. A typical example of a response in this vein was:

‘I believe there is a major shift needed in bringing awareness to hidden disability - I also think people who have a hidden disability are often slow to say they have a disability as they feel they may be taking resources from people who "really" need it - however I believe this leads to even more stigma around hidden disabilities.’

The impact of the common lack of awareness and understanding from others was described by one survey respondent as follows:

‘There can be an assumption that people are faking being disabled when they don’t “look sick”, this is nearly always incorrect. For example, a young person who looks fine, but has severe arthritis and a blue badge, gets abuse from a stranger for parking in a disabled parking space. People should be believed and supported to do their best.’

Lack of understanding of their disabilities by others was also reported as a challenge for children and young people. There was strong consensus among this group that education is key to informing the public about disability, so they have a better understanding of the supports that children and young people might need. One young person with autism explained:

‘I have autism and so I have a problem with focus. They don’t understand what the focus problem is, and they just tell me to focus. They don’t have a deeper understanding. They understand I have Autism or ADHD, but beyond that they don’t understand what to do. I can get undermined, and I say a strategy doesn’t work and I might be called lazy even if I’m trying with every fibre of my being to focus. Unless you have it it’s hard to understand. Focus problems can be different for each person. So, people need to have a proper understanding of the consequences.’

Participants also spoke about a lack of awareness around the needs of people with multiple disability types. For example, it was raised in one focus group that there should be better understanding among the general population that people with Down Syndrome and other intellectual disabilities can also have mental health difficulties or a psychosocial disability.

It was highlighted by a small number of participants, including a DPO representative, that it is discriminatory to view or speak about disabled people as a homogenous group.

### Lack of visibility

Related to lack of awareness was the issue of a lack of visibility of disabled people in Irish society. Examples given were the lack of visibility of disabled people in the media, in the arts, in sport, and in politics. For example, one survey respondent wrote:

‘Another important change would be the social inclusion and mainstreaming of people with disabilities in Ireland. We are so often an afterthought in national campaigns or political movements, in media, etc. So, in short, disability visibility could improve. On this point, I was most impressed by the posters and buses with "disability rights are human rights" written on them in line with the CRPD. This sort of measure is a simple way to increase our visibility in Irish society.’

The importance of public awareness campaigns and of the International Day of Disability for increasing disability visibility was raised. Some participants, however, were critical of previous national public awareness campaigns, expressing the belief that the money spent on such campaigns would be better spent on realising people’s rights rather than advertising that these rights exist.

Other participants spoke of the importance of the visibility of disability in community spaces. For example, one parent wrote:

‘Please support us to take our children out in public without being stared at or made to feel uncomfortable. This has to start with our communities being used to seeing disabled/highly complex kids on a regular basis, and this starts with the school system & local playgrounds. I’d like to think that, in one decade, disabled kids will be more visible and that that visibility will be normalised.'

### Insufficient policy attention

As well as experiencing a lack of awareness or understanding in interpersonal interactions and relationships, the issue of particular types of disability or different conditions being omitted from policy discussions or awareness campaigns was also raised. For example, one participant referred to limb loss as ‘the forgotten disability’. In a written submission, one DPO pointed out that ‘the terms “dyslexia” and “dyscalculia” are underused (and at times actively removed) from key publications, guidelines, and circulars published by Government departments and related agencies.’ One survey respondent spoke about how little public attention is paid to dyspraxia/developmental coordination disorder:

‘Please, please start including Dyspraxia (DCD) in awareness campaigns, education and mental health talks in workplaces, doctors and schools as well as the general public. It is an incredibly overlooked disorder that effects at least one child in every classroom with a massive range of symptoms that make life difficult and leads to the individual being misunderstood, laughed at or seen as “sensitive” or “lazy”’.

A survey respondent explained that people with chronic illnesses who may not identify as disabled but nonetheless experience barriers to functioning are often overlooked in disability policy:

‘Many people living with chronic illnesses don’t identify as disabled people, and as a result they are often left out of disability strategy discussions. However, in reality many people in our communities are living with disabilities such as chronic pain, reduced strength, and crippling fatigue. More needs to be done to support this group. More work needs to be done in acknowledging the disability-causing chronic illnesses that affect women disproportionately. Areas such as autoimmune diseases, migraines, menopause, endometriosis, ME/CFS, fibromyalgia, long covid etc can have life changing implications on people’s function.’

In terms of inclusion and equality policy in Ireland, several participants indicated that they felt that disability comes ‘last on the list’. Other participants questioned the understanding of ‘inclusion’ among policy makers, believing they understand the term as limited to making the built environment accessible for people with physical disabilities, rather than full integration of all disabled people into society. It was suggested that Government views disability as a ‘niche concern’, even though more than 1 in 5 people were identified as having a disability in Census 2022.

Some participants mentioned negative interactions they had had with named politicians, and one participant called for accountability for elected officials who use disability-related slurs in the course of their work.

### Prejudice and discrimination against particular groups

Some consultation participants called out negative attitudes, stereotypes, stigma, fear, and prejudice against specific groups of disabled people. These include people with intellectual disabilities, autistic people, people living in residential facilities for those with disabilities, and people with mental health difficulties.

Several participants also spoke about multiple or intersectional discrimination experienced by disabled people from marginalised groups, including LGBTQI+ people with disabilities, and elderly disabled people who can experience both ableism and ageism. Systemic and institutional racism against Travellers was called out, as well as how this impacts disabled Travellers. For example, Travellers with disabilities can be reluctant to seek out or use services that they need, having had previous negative interactions with the State.

## 5.2.2 Proposed actions and solutions

Consultation participants provided many suggestions as to how lack of awareness, prejudiced attitudes, and discrimination against disabled people could be addressed in the new National Disability Strategy. These mainly related to education and training and to awareness raising activities, and they can be summarised as follows:

### Education, training and awareness raising

* Conduct training and awareness raising among elected officials and staff of government departments, state agencies, local authorities, and NGOs on disability in general and the UNCRPD in particular (contribution by DPOs and others);
* Deliver disability awareness/equality/competence training to all staff delivering a service to the public, including staff in both mainstream and disability-specific services;
* Conduct a review of disability equality training in Ireland to ensure it is fit for purpose and reflects the needs of disabled people (DPO contribution);
* Deliver disability equality training in schools (e.g., by integrating this into the primary curriculum and/or by delivering specific modules/courses in Transition Year);
* Build partnership networks with local Traveller groups and provide high-quality Traveller cultural awareness training to those providing services to disabled Travellers;
* Work towards a society in which disability and difference are not only accepted but embraced and celebrated;
* Make attempts to create a national understanding and empathy for disabled people that is based on equality and a human rights approach. This should target an increase in awareness and understanding of what everyday life can be like for disabled people and on preferred terminology/language in relation to disability (contribution from DPOs and others);
* Engage in specific awareness raising and educational activities surrounding invisible disabilities, including mental health difficulties and chronic illnesses;
* Engage in specific awareness raising and educational activities on autism;
* Deliver public awareness campaigns in the media relating to d/Deaf Awareness and ISL interpretation;
* Promote awareness of the differences between people with low and no vision;
* Promote awareness of disability among children and young people through activities delivered by youth groups or theatre groups in schools;
* Explicitly acknowledge the importance of the words ‘dyslexia’ and ‘dyscalculia’ to those impacted by them and include these words openly in all relevant formal government documents and guidelines, per the UNCRPD’s Right to Identity (DPO contribution);
* Conduct awareness raising and training among professionals, organisations, and communities about the vulnerability of disabled women to abuse; and
* Educate the public on the social model of disability (contribution by DPOs and others).

### Visibility, representation, and pride

* Increase the visibility of disabled people, including children, in public life and in communities;
* Ensure positive representation of disabled people on radio, television, podcasts and in newspapers that challenges stereotypes, guarding against ‘pity’ narratives and what has been referred to as ‘toxic positivity’ (e.g., ‘Autism is my superpower’);
* Promote pride amongst ISL users in their language from a young age (DPO contribution); and
* Introduce a system through which people can indicate that they have a disability without having to declare it verbally (e.g., the Sunflower lanyard for hidden disabilities) and roll this out nationally.

### Legislation and policy

* Introduce robust anti-discrimination legislation and adopt a zero-tolerance policy for disability discrimination;
* Expand the definition of disability used across all state agencies, schemes, and supports to include chronic illness; and
* Adopt a mainstreaming approach to promote the social inclusion of disabled people, including removing the word ‘disability’ from the names of schemes and services.

# 5.3 Accessibility

## 5.3.1 Context and challenges

Accessibility was raised frequently throughout the consultation, particularly by DPOs. It was also a key theme among children and young people who contributed to the consultation. Participants spoke of the importance of accessibility for equality and the realisation of rights, independence, community participation, and social inclusion and belonging. Participants cautioned against narrow understandings of ‘access’ and advocated that the strategy adopt a holistic approach to accessibility that addresses not only physical barriers but also communication, information, and digital accessibility. Such an approach was deemed necessary to ensure that the needs of all disabled people are considered and addressed. Participants discussed the need for more widespread adoption of Universal Design principles as well as increased access to assistive technologies.

Throughout the consultation, participants raised accessibility challenges across a range of domains, and accessibility issues relating to transport, employment, education, health and social care services, and others, are covered in their respective sections. In this section, general accessibility issues and specific accessibility issues not addressed elsewhere in this report are covered. Participants recognised that accessibility is a cross-cutting issue, stating for example that ‘The issue of accessibility is massive. Participants identified a need for more joint thinking between health, finance and disability Government departments and one participant stated that ‘All policy should start from a place of accessibility.’

### Inaccessibility of the built environment

#### Buildings

Participants discussed their experiences of barriers to accessing buildings and the impact of this on their lives. Some spoke about the inaccessibility of public buildings such as local authority offices. Others focused on the lack of accessibility of retail and hospitality spaces. Also discussed was the inaccessibility of local and community spaces. In relation to the inaccessibility of buildings, issues raised include narrow doorways, a lack of push button doors, a lack of ramps, and a lack of lifts (or frequently out of order lifts) in buildings where public services are provided, in businesses, and in private housing. Participants spoke of feelings of frustration and disappointment on finding that they could not access a building they need or wish to.

A small number of participants spoke of accessibility barriers as being greater in rural areas. For example, one survey respondent wrote: ‘The world outside of cities is not accessible to wheelchair users and even government offices such as the social welfare office in some towns cannot be entered by people with physical disabilities.’ It was noted that even in buildings that ‘work well’ for manual wheelchairs, there is often insufficient room for power wheelchair users.

A handful of participants mentioned particular issues accessing older or historic buildings, arguing strongly that these should not be exempt from accessibility requirements. For example, one survey respondent expressed the desire:

‘That all buildings and public infrastructure are made accessible regardless the cost. Historical buildings and those deemed excluded from adaption should be made accessible as it was the fact disabled people were originally excluded from the planning of these buildings that meant they weren't accessible to start with. This is not our fault.’

While many contributions related to the accessibility of buildings to individuals with physical and sensory disabilities, such as wheelchair users and people who are blind or vision impaired, some consultation participants spoke of accessibility for people with autism and mental health difficulties. For example, one participant argued in a written submission:

‘There is a need to ensure that access is sense checked against psychosocial factors as well as physical ones. That sensory issues, social anxiety-inducing factors and in general neurodiverse considerations are taken into account when one looks at accessibility issues.’

#### Roads and pathways

Consultation participants frequently raised issues with roads and pathways in towns, villages, and rural areas. In relation to urban areas, several consultation participants spoke about the obstruction of paths by parked cars, restaurant seating, plant pots, etc. Others spoke about uneven surfaces and how these cause difficulties for wheelchair users: ‘The roads and pathways are terrible. No consideration when bits of tar are added to roads in clumps how this impacts wheelchair users.’ Travelling on cobbled pathways was described as uncomfortable for wheelchair users. It was also reported that it is difficult for wheelchair users to manoeuvre on and off pathways due to the height difference between the path and the road and the lack of kerb ramps. Other issues raised included insufficient numbers of pedestrian crossings and the inaccessibility of many car parks.

In discussing accessibility, independence was a key theme among children and young people, particularly for those with physical and sensory disabilities. As one participant explained:

‘I don’t want to be holding hands with my Mam my whole life…I am stuck even though I am an 11-year-old because the environment is not right. No-one else my age, other than children with disabilities, do that…If paths and roads were better, habits would not have to form at a young age…I could be more independent.’

#### Toilets

The issue of the accessibility of toilets was raised repeatedly over the course of the consultation. Participants spoke about a lack of public wheelchair accessible toilets. In establishments where there are ‘accessible’ toilets, participants described these as frequently locked or often having emergency cords cut or tied up. Other issues included that purportedly accessible toilets are often actually too small, and ‘only good enough for people with minor disability’. The impact of too few or unsuitable toilets was described: ‘This can lead to some people being self-conscious or staying at home.’

Participants argued that there are nowhere near enough Changing Places toilets in Ireland. One participant cited that there are over 1,300 Changing Places toilets in the UK, compared to just 19 in Ireland.

### Inaccessible services

Participants spoke of barriers to accessing services, including banking and financial services, customer service or support, dental services, beauty services, and recycling services. It was reported that there was a lack of consideration as to how these everyday services could be accessed by people with diverse needs.

Participants also felt that there is a need for clarity on the duty of charity or voluntary sector service providers to provide access to Deaf ISL users, especially when entirely or largely funded by public monies.

### Inaccessible and insufficient information

Participants spoke about having insufficient accessible information and advice to assert their rights or to navigate the world successfully. Consultation participants cited a lack of information on disability matters as a particular concern. Participants spoke about a lack of accessible information on elections and voting, inaccessible weather alerts and other warnings, inaccessible signage, and inaccessible websites, including Government websites. It was noted that Government graphics including infographics tend to be inaccessible to blind people, and there is no attempt made to represent complex data, for examples, trends and graphs, in an accessible way for those who are visually impaired. Accessibility issues related to a lack of video messaging, a lack of braille versions of material, publication of material that is inaccessible to screen readers, lack of captions or subtitles on video information, and a lack of provision of ISL information on public announcements in settings such as train stations, airports, etc., as well as on television. Participants spoke about insufficient provision of Easy Read material or material presented in a manner that does not require reading. For example: ‘Everything is about texts, emails, social media, but I can’t read so most of it is no good to me. Videos are better for me.’

Some participants spoke about feeling excluded from their communities by a lack of accessible information for people with communication and literacy support needs or with autism. This was described as impacting their participation and engagement in community life. Examples of responses in this vein include:

‘I would like to learn how to read and write so I can take part in more things. I feel a bit left out of some things.’

‘I wish people in the community would give us information in words and sentences that we can understand.’

‘I wanted to join a course, but I couldn’t book a place because the website and instructions were too hard to understand.’

### Inaccessible communication

As well as barriers receiving information in accessible ways as just described, barriers to communicating were frequently reported by consultation participants. Communication barriers were described as greatly impacting on people’s functioning and well-being. This issue was raised most frequently by DPO representatives and others as an issue for the Deaf community. It was raised consistently as an issue that there is an acute shortage of ISL interpreters in Ireland, that interpreters are not being trained in sufficient numbers, and that Ireland lags behind other countries in terms of interpreters per capita.

Communication barriers were reported as impacting people’s ability to conduct everyday activities. For example, ISL users described issues accessing services over the phone, with some entities (e.g., utilities providers) refusing to speak to an ISL interpreter or other third party for data protection reasons. In a written submission, a DPO described the issue as follows:

‘Members of the Deaf community are exhausted from trying to integrate into the hearing world. Finding an available interpreter for communicating with public services is exhausting. It is very expensive. Every Deaf person has to plan their interactions to the point of exhaustion.

Most Deaf people prefer to have an interpreter in the room with them when it comes to health or personal issues, not online interpreters.’

One DPO raised the need for better communication supports for deafblind people. The UK was highlighted as having an excellent system of such supports that could be used as an example.

### Insufficient access to assistive technologies

Assistive technology (AT) is an umbrella term, referring to the practical tools used to support the functional needs of persons with disabilities. It includes physical products, such as hearing aids and magnifiers, as well as digital solutions, such as a talking clock or speech generating software. One subcategory within the field of assistive technology is augmentative and alternative communication (AAC) equipment. The use of AT can help to improve or maintain a person’s functioning in terms of cognition, communication, hearing, mobility, vision, or self-care. Many people will use more than one kind of AT at a time, resulting in a need for integrated services. There are various types of AT available, (including high/low tech options) with many factors to consider in the context of personal requirements e.g., ease of use, size/weight, cost etc.

Consultation participants welcomed the use of AT to enable access to education, employment, and independent living. It was characterised as a human right and a precondition for community participation, supporting communication, rehabilitation, independence, and improved quality of life. People with disabilities felt technology must be prioritised, to make their everyday lives easier.

It was highlighted that digital assistive technologies such as speech recognition software, screen readers, alternative access devices such as switches and eye gaze technologies, along with environmental control technologies allow people with disabilities choice and control.

There were calls to expand provision of AT at a national level and provide straightforward access to equipment. People with disabilities experienced difficulties in this regard, including an ‘arduous’ funding process. It was noted that many disability service providers did not offer support around access to, or use of AT. Consultation participants highlighted the importance of ownership or use of devices being tied to a person, rather than a service, so that they can be brought with them when transitioning from one setting to another.

Consultation participants recognised the need for timely access to services. While a multi-disciplinary approach may be required for those with high support needs, this is not always the case. There were calls for a replacement for the Assist Ireland website (which shut down in 2019) to allow users to be better equipped to source their own AT options. It was felt there was potential for huge cost savings, supporting people to live in their own homes and reducing need for long-term residential care. However, focus group participants stressed that AT is not a substitute for personal assistance, and hours saved through its use must be reallocated.

Written submissions highlighted the positive impact of virtual disability services in the wake of the pandemic. They also welcomed the funding of AT initiatives by government, including CREATE.[[16]](#footnote-17) Consultation participants understood that digital technologies are ever-present, and they noted that Artificial Intelligence (AI) has the potential to be a double-edged sword.

A small number of participants raised the issue of the availability of plastic straws (also a form of AT) in hospitality establishments for use by disabled people who need them, arguing strongly that the paper or biodegradable straws now typically offered are not appropriate. For example, in one written submission, it was noted:

‘Straws for use by disabled people must not be biodegradable or paper-based – they must be plastic… Straws are part of disability history and are one of the first examples of Universal Design. They were made for use in hospitals. Once disabled people achieved greater independence to live in non-medical facilities, they promoted plastic straws as an access tool. As a result, any disabled person can go into any bar or restaurant and get a drink. Being able to get a hot or cold drink in Irish social settings is important for all disabled people.’

## 5.3.2 Proposed actions and solutions

Consultation participants provided many proposals for removing common accessibility barriers and for making Irish communities and society more accessible to disabled people. Suggestions related to addressing the accessibility of the built environment, services, information and communication and availability of assistive technology in the National Disability Strategy, and are summarised as follows:

### Policy

* Address accessibility as a key priority of the National Disability Strategy;
* Recognise the cross-cutting nature of accessibility and adopt a joined-up approach to addressing accessibility issues;
* Redirect policy-based funding; hire access officers to tackle local issues (DPO contribution); and
* Keep accessibility at the centre of all policy.

### Built environment

* Require all public buildings to be accessible to all individuals, including people with physical, sensory, and psychosocial disabilities. Enforce these equal access requirements;
* Make all buildings and public infrastructure accessible, regardless of the cost, and without making older or historical buildings excluded or exempt from adaptation;
* Provide funding to allow businesses and community groups to make their buildings accessible. Introduce a voluntary grant scheme for businesses with a view to making it mandatory within five years, including penalties if businesses do not comply;
* Make changes to planning/building legislation to ensure that all new buildings and public spaces are designed in line with Universal Design principles;
* In addition to entering and exiting a building, consult with disabled people about accessible layout of rooms within buildings;
* Introduce more public toilets that are fully accessible. Accessible toilets should be low sensory spaces, for example, low lights, no hand-dryer, no music, quiet flush;
* Have more gender-neutral accessible toilets so that people can be supported by different family or staff members;
* Introduce more Changing Places toilets (e.g., one in every town in Ireland);
* Encourage the implementation of more disability-friendly or autism-friendly public spaces, such as quiet zones at public events, or specified times in retail outlets, cinemas or other entertainment or commercial spaces when noise is reduced, lights dimmed, announcements minimised, noise cancelling headphones available, etc;
* Actively address hazards in the built environment, for example by requiring glass doors to be marked or etched so people do not walk into them, clearly marking overhanging windowsills or window boxes so children do not walk into them, and more clearly signposting traffic cones, roadworks, and construction sites;
* Improve signage in the community and in public buildings, including having signs in large font and braille, or with images. Signs should be in a consistent place, for example, on the door or beside the door so a person knows where to find them;
* Ensure every local authority has a dedicated access officer working on access issues (contribution from DPOs and others);
* Require local authorities to undergo access audits with their local community groups;
* Address the accessibility of pathways by levying penalties for people who obstruct pathways (through parked cars, restaurant seating, etc.,), avoiding use of cobblestones, having wider, level pathways, and creating more areas where wheelchairs can move to and from the path to the road easily;
* Introduce better and more pedestrian crossings; and
* Align the Design Manual for Urban Roads and Streets (DMURS 3) with the UNCRPD.

### Information

* Ensure provision of accessible information (Easy Read, video, ISL, braille, etc.,) on a range of important topics including elections and voting, public consultations, weather warnings and other alerts, and the rights of disabled people (contribution from DPOs and others);
* Consider how information can be made accessible to all children and young people;
* Utilise technology, and in particular apps, to give people information about the accessibility of places and services in their community;
* Foster common high standards for accessible information, including Easy Read, ISL interpretation, and making documents compatible for screen readers;
* Promote website accessibility and ensure the accessibility of government websites;
* Advocate for the inclusion of accessibility features in mainstream technologies and platforms; and
* Provide a centralised communications or information platform on disability matters and a database of all disability organisations.

### Communication

* Increase access to ISL interpretation services in various settings, including public services, education, healthcare, and legal proceedings (contribution from DPOs and others);
* Create new fast-track apprenticeship routes to becoming an ISL interpreter or ISL teacher, as well as fast-track accreditation for ISL interpreters;
* Create more centres for training ISL interpreters. Locate these throughout the country and not just in Dublin (DPO contribution);
* Fund local pilot projects to hire full-time interpreters to serve the Deaf community (e.g., a proposal by the HSE Gold Star Disability Project in Tipperary and the South Tipperary Disability Groups Forum) (DPO contribution);
* Ensure 24/7 access to ISL interpreters, including for emergencies (DPO contribution);
* Ensure legal protection and support for the linguistic rights of ISL users;
* Require private sector organisations to cover ISL interpreting costs;
* Fund a master’s degree in ISL interpreting to address the national shortage of ISL interpreters;
* Fund additional tutor and support hours in the current Bachelor of Deaf Studies in TCD Centre for Deaf Studies to ensure higher numbers of graduates;
* Fund and adequately resource the Register of Irish Sign Language Interpreters (RISLI);
* Fund CPD for ISL interpreters to improve and maintain the quality of the profession;
* Develop standardised guidelines for ISL interpretation and d/Deaf Awareness;
* Move the Sign Language Interpreting Service (SLIS) to a human rights-based funding model under the Department of Children, Equality, Disability, Integration and Youth, away from the current social welfare annual-funding model under the Citizen’s Information Board (CIB) and the Department of Social Protection;
* Require RISLI or the Teaching Council to establish a separate register to regulate ISL teaching, ensuring quality is maintained in the ISL teaching profession;
* Increase the use of technology to enhance communication access, such as greater use of video relay services and captioning;
* Promote more widespread use of ISL, Lámh signs, pictures, and photos in Irish society;
* Introduce better communication supports for deafblind people (DPO contribution); and
* Ensure communications conform to relevant standards e.g., EN 301 549 ‘Accessibility requirements for ICT products and services’.

### Services

* Employ more Access Officers. Provide information to disabled people, including children and young people, about what Access Officers do and how they can help individuals;
* Appoint Disability Officers to each local authority, equipped with powers of enforcement;
* Encourage every business and service to have an access plan underpinned by a respectful and person-centred approach to people with diverse needs; and
* Offer services remotely as well as in-person, where possible.

### Assistive technologies

* Include a dedicated section on AT within the NDS;
* Invest significantly in the development of a national AT ecosystem, both in the technologies themselves and the services/supports to ensure that those who need them can get them in a timely manner;
* Re-establish a national website on AT that provides reliable information;
* Ensure that AT is assessed for and issued by suitably trained, experienced staff. Provide training for the recipient, follow-up, and information for their circle of support;
* Ensure that AT assessments are universally available i.e., service users need not reach a threshold to apply;
* Fund the recruitment of skilled staff to support people with disabilities and service in using AT;
* Provide multi-annual funding for AT services to ensure a scaling up of accessible services and the recruitment/retention of qualified, experienced personnel;
* Grant AT to individuals, not organisations;
* Recognise that AT needs will change across the lifespan. Allow people with disabilities to engage with AT services at multiple points in time;
* Provide joined-up AT services through the HSE and beyond, including forums and grants for those who do not have medical cards;
* Place the onus on mainstream educators to accommodate AT users;
* Increase AT funding for employers and employees (including training and repairs);
* Introduce technology solutions in public buildings to ensure accessible signage (e.g., The NaviLens app or similar. NaviLens scans QR codes to create accessible signage for those with visual impairments or other print disabilities, e.g., dyslexia);
* Provide equipment to support reading and writing for people with disabilities;
* Develop and promote AT that enhances communication and accessibility for Deaf people;
* Embrace accessible, mainstream technologies within the State procurement remit to maximise cost efficiency e.g., tablets, smartphones;
* Resource local authorities to provide smart homes for people with disabilities in their local communities;
* Develop digital literacy skills courses to support for people with different types of disabilities;
* Consider the role of technology more widely to accommodate online services via an innovative funding model;
* Ensure on-going funding for established virtual service programmes that have shown value for those accessing them;
* Develop and widely disseminate best practice guidelines for digital content design to ensure accessibility;
* Use AI to map out needs and generate ideas for cheaper technology e.g., vision glasses;
* Introduce a legal requirement for all hospitality establishments to have plastic straws available for use by disabled people; and

### Other actions

* Promote greater use of assistance dogs for children and adults with disabilities.

# 5.4 Health and social care services

## 5.4.1 Context and challenges

Health and social care services for disabled people featured prominently throughout the consultation process, with the majority of consultation participants highlighting unmet need for and difficulties accessing primary care and disability services. Consultation participants reported challenges and barriers to accessing assessments, services, and supports, including a failure to deliver or a lack of availability of services, long waiting lists and times, and geographic variations in the provision and quality of services. Many of these difficulties were attributed to a lack of adequate funding and staffing, with lack of multi-annual funding cited as a particular barrier to long-term service planning for voluntary organisations providing services on behalf of the State.

Primary concerns raised during the consultation process related to barriers to receiving early intervention services, multidisciplinary supports, children’s therapies, and respite services for both children and adults with disabilities. The common thread throughout many of participant’s concerns was a demand for access to and the provision of timely, equitable and quality health and social care services which are appropriately resourced and staffed.

### Availability and adequacy of services

Consultation participants voiced strong concerns about the lack of available health and social care services. Participants criticised a service delivery model based on resources rather than demand. It was also noted that disabled people face health inequalities and that unmet needs for services can negatively impact their health, wellbeing, and human rights. Some highlighted the challenges which people with intellectual disabilities experience, with one submission pointing to a recent Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) report that revealed that people with intellectual disabilities do not have the same access to healthcare as others in society.

Participants voiced concern about the lack of joined-up services that results in disabled people falling through the cracks. Others highlighted inadequate forecasting for future health and social care needs. For example, one submission noted that, according to the Department of Health’s Disability Capacity Review to 2032, demand for therapy services is expected to increase by about two-thirds by 2032 due to unmet needs and demographic changes. It was noted that lack of planning for the future needs of individuals can cause additional worry and stress for the parents of adults with disabilities. There was also criticism of long waiting lists and times for health and social care services and of the ‘postcode lottery’ and geographical variation in services, which are forcing some to access private services or to seek treatment abroad. As one participant explained:

‘There are extremely long waiting lists in parts of the country. People have to go private. People have to travel abroad. So many obstacles are put in front of people.’

One submission attributed variation in the standard and quality of disability services to the fact that most services are delivered by different voluntary organisations.

Several parents spoke about the lack of disability services, multidisciplinary supports, and therapies for their adult children, with one parent noting that their adult child is non-verbal and awaiting physiotherapy for the past three years. There were also concerns regarding shortfalls in the availability of multidisciplinary teams and lack of access to adult therapies and assessments, with one DPO submission referencing lack of assessments for dyslexia and dyscalculia for adults and other associated matters.

Lack of local and community supports and services was also raised, including a dearth of community-based neuro-rehabilitation services and community support services for stroke, heart failure and other cardiac conditions as well as people with epidermolysis bullosa (EB), polio survivors, and amputees. Implementation gaps relating to Sláintecare, including as regards primary and community care, were also highlighted.

Some participants noted that lack of adequate community primary care supports can negatively impact the health and wellbeing of disabled people. It was also noted that this can result in an over-reliance on nursing home placements, including the inappropriate placement of young people with disabilities in nursing homes, as highlighted in the Ombudsman’s 2021 Wasted Lives report. One submission noted that while there is an ongoing initiative to move these young people into community settings with support, it has been slow to gain momentum.

One submission noted that there can be a perception that disabled people should avail of and have access to disability-specific services, which may not always be appropriate or necessary. Another suggested that there is a sense that disabled people have to fit into a model of care offered by services, rather than services providing individualised care. A small number of submissions voiced concern about lack of adequate neurological supports, including inpatient facilities. For example, it was noted in one submission that Ireland has only half of the rehabilitation beds needed for a population of its size, all of which are concentrated in the Dublin area, and that waiting lists for the only National Rehabilitation Hospital in Dún Laoghaire frequently exceed 300 patients at any one time, with waiting periods of up to six months.

Other issues mentioned included:

* outdated models of service provision
* lack of a comprehensive specific stroke service
* gaps in access to specialist healthcare services for individuals with intellectual disabilities who are in full-time higher education

### Accessibility of services

DPO representatives and other consultation participants highlighted barriers regarding the accessibility of health and social care services, including mainstream services. One submission noted that the barriers experienced by disabled people while accessing services can negatively impact wellbeing. Accessible communication was identified as a particular issue, with several reports of difficulties accessing ISL interpretation, including from a DPO representative. For example, it was stated that such difficulties have given rise to situations where the children of Deaf adults have had to interpret for their parents when visiting the doctor or a primary care facility, and that ISL interpretation is often not provided due to a lack of awareness amongst health and social care professionals. Some participants also complained about health and social care providers refusing to accommodate communication preferences. Examples cited included a GP refusing to communicate with a d/Deaf person via text or email and written appointment notifications being sent to people with a visual impairment. A d/Deaf participant also objected to having to register for a service enabling them to text 112 in an emergency, while another consultation participant drew attention to the lack of communication supports for those with literacy difficulties.

Additionally, participants underscored that health and social care environments should be physically accessible and take account of the potential sensory overload that may be experienced by some, with one DPO representative noting that access audits are often lacking. Physical barriers highlighted included difficulties accessing scans and X-rays for those using wheelchairs or people who require the assistance of a hoist, lack of accessible facilities in nursing homes, difficulties accessing GP premises which only have stairs, and difficulties accessing bathrooms, including in hospitals.

### Funding and staffing

Consultation participants raised concern about insufficient funding for health and social care services, particularly disability services. It was noted that long waiting lists and unmet needs will persist without appropriate funding and staffing, and that demand for services is only increasing. One DPO representative asserted that healthcare in Ireland is based on the medical model, while another participant criticised the use of means-testing to govern access to supports and push people towards private services. Some submissions identified specific areas where additional funding is required, including children’s disability services, respite services, neurorehabilitation services, and Child and Adolescent Mental Health Service (CAMHS) services.

Voluntary organisations providing supports and services also referenced funding challenges, citing the lack of multi-annual funding arrangements as a barrier to sustainability and the planning of services over the long term. It was also noted that disability services are challenged by historical underfunding, compounded in recent years by inflationary pressures, a recruitment and retention crisis, growing unmet need, and changing needs not being funded. The absence of a policy or strategy defining the role of the voluntary sector in delivering disability services for which the state is responsible was identified as an issue.

The Section 38 and 39 structure of service delivery was described as inefficient and ineffective, with one submission also citing difficulties accessing Section 39 funding for new organisations and those providing wellness services. There was also a sense from participants that there is a lack of clarity in relation to the resources needed and the funding available to implement the Disability Action Plan 2024-2026.

In addition to resourcing, staff retention and recruitment issues featured prominently. Participants noted that some staff are choosing to emigrate for better pay or move to a different sector, and there are particular challenges filling posts outside of Dublin. Some felt that it was unfair that those who are training to work in social care have to work without pay. Staffing shortfalls were identified in several areas, in particular health professionals within multidisciplinary teams. It was also noted that high staff turnover and a reliance on agency staff can cause difficulties for disabled people, as familiarity and trust with staff are important. In addition, it was reported that staff are experiencing burnout and lack resources to provide a comprehensive service or care, with some choosing to leave their profession. Some participants also criticised the lack of pay parity between Section 39, Section 38 and HSE staff, with one submission asserting that Section 39 organisations delivering essential disability services are in crisis in terms of staff retention and recruitment:

‘For organisations to be able to recruit and retain high-quality staff, they must show existing staff members and prospective candidates that they are valued equally; paid equally for the same work, whether they work for a Section 38, Section 39 organisation or the HSE.’

It was also stated that Section 39 organisations are being forced to use agency staff to fill staff shortages, causing cost overruns. One submission attributed these staffing shortages to the HSE’s refusal to permit Section 38 and 39 organisations to recognise the prior experience of social care staff, meaning that staff would have to enter at the bottom of the salary scale.

Other issues reported included the inefficiency of Garda vetting systems, which can lead to delays in staff recruitment, language barriers between home care staff and people they are supporting, as well as a lack of trained resource specialists in amputee care.

### Cross-cutting issues

Consultation participants reported that lack of both digitised health and social care information and joined-up thinking across services presents challenges to the delivery of care for people with disabilities. For example, there were reports of a lack of available and affordable transportation to local health and social care services. One submission noted that while interagency collaboration exists and progress has been achieved, this could be strengthened through clear lines of accountability, regular reviews, and close monitoring.

Other issues included lack of data on levels of unmet need and lack of accountability for the failure of providers to deliver services. One participant considered the five-year forecasts of future need by the Health Research Board National Ability Supports System as limiting, while another criticised the IT systems maintained by some Section 38 and 39 organisations. In addition, a written submission placed a particular focus on adopting a human rights-based approach to health and social care data, including by providing transparency regarding how and why data is collected, used and shared, and ensuring that people’s will and preferences are reflected in decisions regarding how information is managed and governed.

A DPO representative and other consultation participants described difficulties accessing medical records and challenges finding information regarding services and entitlements at the appropriate time (e.g., following a diagnosis). They described negative attitudes towards and lack of understanding of the needs of disabled people, including people with intellectual disabilities and people who are non-speaking. For example, it was reported that some staff failed to speak directly to the disabled person themselves or did not allow the necessary time or provide encouragement for people to speak or communicate. Participants emphasised the importance of feedback and listening to those with lived experience, as well as disability awareness training, including on hidden disabilities.

Participants also reported challenges related to assistive technologies (AT) such as ‘aids and appliances’ provided by the HSE. They reported long delays accessing and lack of available supports for AT. Some reported being forced to purchase expensive items privately, with others forced to wait or use inappropriate equipment.

There was also criticism that AT is not reused and recycled, leading to waste, and that those working full-time do not satisfy the means test and are therefore obliged to purchase their own aids and appliances. One submission pointed out that there is no national policy as to how state bodies can best cater for the assistive and mobility needs of amputees across the country.

### Day services

Consultation participants reported that day services are experiencing staff and funding shortages, limiting access and their ability to achieve goals in person-centred plans, many of which relate to activities in the community. Participants complained that staff hours in day services were often inflexible. They said progress achieved before COVID-19 has been lost, restricting people’s social lives, including opportunities to undertake activities in the evenings or at weekends and to travel abroad or take short trips. That said, where support was available, participants praised the work of staff and their commitment to supporting them to live their best life.

Some staff in day service provision supporting people with intellectual disabilities outlined how they try to limit the personal goals of attendees due to funding constraints. Other participants raised the issue of private transport resources in day services, with many explaining that there were limited options and space for those wishing to use them, including a lack of wheelchair spaces. A combination of staff shortages, lack of public transport, and limited private transport options means that it can be difficult to accommodate individual requests, and either large groups of people have to go out together from a day service or large groups stay in the centre all day. As one participant said:

‘If I want to do a course in X (name of college) then I need to take the bus so either other people have to come with me, or they stay in all day. There is no public transport to get me to X (name of college).’

Other issues raised regarding day services included geographic variations in access, lack of oversight and inspection, barriers to the provision of employment supports for those with intellectual disabilities attending day services, and failure of some services to adhere to the New Directions policy. Some consultation participants criticised the day service model, with one describing it as ‘draconian’, and others highlighting how people are fearful of raising concerns. One person was under the impression that individuals are now being charged for day services and expressed strong disagreement with this[[17]](#footnote-18).

### Respite services

Consultation participants consistently highlighted inadequate provision of respite services for both adults and children with disabilities, with one individual noting that he has had to ‘go from pillar to post’ seeking support for a disabled adult, and another adding that respite care is ‘drying up all over the country’. One submission spotlighted an investigation by the Ombudsman for Children which found that respite services are inadequately resourced and inconsistently provided to children across the country. Other respite concerns related to inadequate funding and lack of staffing, inconsistent access throughout the country and barriers to community participation.

The impact of lack of access to respite services on carers and parents was described. Participants reported that ‘parents are at their wits end’ due to a lack of respite services, resulting in burnout for parents and carers, a reduced ability to care, and regular reliance on the hospital system. Lack of choice of respite services was raised, as well as difficulties transporting equipment to residential respite settings due to the lack of availability of home-based respite.

### Residential care services

Consultation participants reported staff shortages in residential care services, preventing people with disabilities from seeking new experiences and opportunities in the community. For example, one participant reported that a parent was advised that the only way she could access residential care for her child was to put them into respite services and refuse to take them out. Participants, including some living in residential services, expressed frustration that staffing levels are no longer sufficient in their organisation to support activities, including short breaks and holidays:

‘There is not enough staff…some days it is fine with staff but if a staff member is sick or on holidays or on maternity leave then we can be very short. It is very hard to get new staff now.’

It was also noted that there is a lack of appropriate residential care placements, with one submission outlining that these shortages can result in long-term hospital stays for adults with intellectual disabilities, discharges to nursing homes, inappropriate placements in psychiatric institutions and the offer of a residence far away from family and natural supports. One participant also indicated that certain residential care staff can refuse to undertake duties or provide certain forms of care due to governance reasons.

In addition, concerns were expressed about lack of planning for future residential care needs, lack of individualised care in services, lack of effective oversight of all residential care facilities and the paternalistic treatment of adults with disabilities, including house rules prohibiting partners from staying overnight. The lack of choice regarding residents who share the accommodation was also raised. Issues relating to transitioning from congregated settings is covered in the section on independent living below.

### Children’s disability services

Consultation participants highlighted persistent barriers to accessing assessments of need, early intervention services, multidisciplinary supports and therapies from children’s disability services, including speech and language therapy, occupational therapy, psychotherapy, and physiotherapy. One participant stated: ‘Access to services in the country from the day children are born is a fight and a struggle every day.’

Participants reported long waiting times for obtaining assessments of need for their children and complained that a statutory entitlement to an assessment of need, rather than a service, has resulted in the redirection of significant health service resources into reducing waiting lists for assessments rather than the delivery of interventions.

Many parents shared deeply personal stories detailing the negative impact that lack of services, therapies, respite, and early intervention services are having on their children’s lives (many with autism), including mental health impacts. They reported that children have difficulties attending school or are remaining in hospital due to insufficient supports and services in the home. Adverse impacts on parents and the wider family were also highlighted, with one parent deprived of the opportunity to work and another forced to consider placing their child into residential care due to a lack of respite services. One consultation participant stated:

‘Access to services has been non-existent. We feel invisible, pushed out and like we don't exist. We struggle every day, every night, 365 days a year and there's no help at all. Mental health for all family members are in decline and the unbearable stress becomes too heavy to carry. Everything seems too hard and impossible to obtain. There's no guidance, there's no help. Raising a child with complex needs in Ireland is the most isolating and terrifying life.’

Parents reported a range of barriers accessing therapies, including long waiting lists, inadequate quality of services and future planning, and lack of services and supports even where an assessment of need is completed. One parent stated that their non-speaking child is only receiving speech and language therapy and occupational therapy once every three months, while another informed that they must wait nine months before their child with autism can receive any therapy. They reported that they are being forced to access private services and therapies, with one parent signalling that they are ‘sacrificing household needs’ to access support privately and another submission suggesting that such costs can cause anxiety for children.

There was criticism of the Progressing Disability Services for Children and Young People programme, including the level of supports provided by Children’s Disability Network Teams (CDNTs), with one consultation participant describing them as ‘not fit for purpose’. Inadequate staffing levels within CDNTs was identified as an issue, with a few participants attributing this to issues including moratoriums and embargos on recruitment, poor pay, and human resources issues. One participant said:

‘Why can’t they put their hands up and say Progressing Children’s Services has failed… it has failed.’

Lack of communication between CDNTs and other services, lack of consultation with families and disabled children, goals not being met, the poor roll out of Family Forums, ‘red tape’ for staff, and unclear referral forms were also raised. There was also a perception that there is a requirement for a diagnosis to access CDNT supports.

Parents also highlighted a lack of therapy supports within schools, including special schools, and lack of services during school breaks, particularly for those who cannot access a summer programme and may experience regression. One DPO submission also stated that the National Educational Psychological Service (NEPS) does not provide dyslexia or dyscalculia assessments that meet the level of demand from parents or schools. A DPO representative and other consultation participants highlighted lack of supports for children transitioning into adult services and the possibility of losing services when they turn 18, underscoring the importance of joined-up working across health, welfare and education. Particular transition challenges can arise for those with intellectual disabilities and cause additional stress for families. A participant highlighted the challenges they experienced:

‘When I was finishing up in school I didn’t know where to go. I could see all my other friends in different services and I was not able to get into those services.’

### Home care services

A DPO representative and other consultation participants raised issues with the lack of availability of home care supports and the lack of qualified carers, with one participant attributing the latter to inadequate pay. A DPO stated that the lack of qualified carers is forcing some families to seek private personal assistants and another participant stated that disabled people are not receiving their full allocation:

‘Home care or support must be made widely available. Many families including mine require home nursing. Some require carers. Very few families have what they need as even if you are granted the support the staff aren’t there to do it. This is how it is for my family. What little support is offered is only in theory as it’s impossible to fill the hours. We only have 40 hours nursing per month and no respite since my son turned 18. We are lucky to get 10-20 [hours] filled.’

One consultation participant also voiced concern that people who undergo ostomy surgery[[18]](#footnote-19) are automatically provided with home care, without the choice of learning how to care for themselves.

### Child and Adolescent Mental Health Services (CAMHS)

Some consultation participants raised serious concerns about insufficient and inadequate CAMHS provision, as well as a lack of regulation of CAMHS under the Mental Health Act. One participant complained that access to CAMHS is only for those with the highest level of need, such as children who are suicidal, and that supports for families are lacking, while another parent informed that they were left with no choice but to place their child in care due to a lack of mental health supports.

Some of these difficulties were attributed to inaccessible services and a lack of resources and joined-up thinking with CDNTs and disability services. For example, one submission pointed to a 2023 report by the Mental Health Commission which highlighted how the lack of a specific CAMHS budget hindered Community Healthcare Organisations (CHOs) in their planning and led to unavoidable competition between adult and children’s mental health services for funding.

Another submission cited critical reports from the United Nations, Ombudsman for Children, and the Mental Health Commission, with a 2023 report from the latter finding that not one CAMHS team is fully staffed, and some teams operate at below 50% of the clinical staff. These reports highlighted a wide range of issues with CAMHS services including long waiting lists, lack and variations in staffing levels and different disciplines leading to inequalities across CHOs. One submission outlined some of these shortcomings:

‘In the past 12 months, reports from the Mental Health Commission and the United Nations Committee on the Rights of the Child have highlighted serious concerns about the insufficient and inadequate mental health services for children. Portraying an overwhelmed and poorly governed system with inadequate staffing and resources.’

Strong concerns were raised about access to mental health services for children with autism and intellectual disabilities, including reports of autistic children with suicidal ideation being turned away by CAMHS. For example, one submission reported that children with intellectual disabilities are no longer accepted by CAMHS but are to be seen by the specialist service CAMHS for Children with Intellectual Disability (CAMHS-ID) which is experiencing a lack of adequate staffing. This submission also voiced concern about the denial of CAMHS support to children with autism and coexisting mental health issues, with an ‘exclusionary clause’ in CAMHS Operational Guidelines 2019 setting out that admission can be refused to children with autism ‘where there is an absence of a moderate to severe mental disorder’.

### Adult mental health services

There were some reports of difficulties accessing quality, well-resourced and accessible adult mental health services, including long waiting lists. There was a view that mental health services are not prioritised, with one consultation participant describing services as ‘below par’. A submission noted that many actions from the current national mental health policy, Sharing the Vision, are categorised as having 'major delivery issues due to funding constraints' and that Irish expenditure on mental health services compares less favourably against other European states.

DPO representatives highlighted lack of implementation of the previous mental health policy, A Vision for Change, difficulties accessing remote mental health services, a lack of mental health services for d/Deaf people, and particular difficulties accessing ISL interpretation for mental health services. Submissions also referenced the need for appropriate mental health supports for amputees and those with EB, and there was an assertion that some adults with autism and ADHD are being misdiagnosed with mental health issues.

### Hospital care

A small number of consultation participants voiced concern about lack of adequate care within and long waiting lists for hospital services, including for scoliosis treatment. There were also complaints about food in hospitals and access difficulties for people with physical disabilities. Some concerns related to the treatment of the parents and carers of adult children in hospitals, with one consultation participant signalling that their carer was not allowed to support them in hospital, despite their needs being ‘above what a nurse has the capacity to do.’ Another participant expressed concern that they would not be allowed to stay overnight in a hospital with their adult son or daughter with high support needs once they turned 18.

### Intersectional groups

Consultation participants raised challenges faced by people with disabilities who are part of other marginalised groups. Asylum seeker parents of children with autism highlighted difficulties and delays accessing therapies, adding that lack of services can be especially challenging for autistic children living in communal and small spaces and who lack time outdoors. One DPO representative stated that women with disabilities, including women with autism and physical disabilities, can experience situations whereby health professionals do not believe their experiences of pain because they may present differently to other women.

It was reported that LGBTQI+ people with disabilities can experience challenges connected to accessibility, discrimination, and understanding when accessing healthcare. One participant who identified as non-binary reported that they had to hide their identity and identify as a woman to receive appropriate care for their endometriosis. Other examples cited included a lack of understanding of same-sex parents within CAMHS and lack of recognition of lesbian relationships by the National Rehabilitation Hospital. There was also a call for better mental health supports for trans people, with some having to obtain care abroad.

Participants noted that mental health issues are prevalent within the Travelling Community, including high rates of suicide. Racism, ableism and lack of understanding of the lived experience of the Travelling Community within disability and health services were identified as issues. Some consultation participants also complained about lack of follow-up care for Travellers with disabilities and the lack of a joined-up approach across services, including disability services failing to link in with local Traveller organisations. One participant described the extent of mental health issues within the Travelling Community as follows:

‘Mental health issues are absolutely a pandemic really within the community and that's manifested in the levels of suicide in the community, which is seven times higher than the national average.’

Participants raised challenges for Travellers accessing children’s disability services (sometimes due to a lack of awareness of their availability) as well as difficulties accessing care, assessments, and appropriate diagnoses. It was asserted, for example, that some diagnoses are missed because models of assessment have an in-built cultural bias, and that Traveller children, including those with ADHD, are being overprescribed medication. Other concerns related to Travellers missing doctors’ appointments and having to wait weeks for another appointment, as well as a lack of physical accessibility of the venues where local Traveller community groups are located and where they provide their services from.

Consultation participants also welcomed some initiatives, praising the work of the Traveller Counselling Service as well as collaboration between Traveller organisations in Cork and Kerry and the HSE’s Mental Health Service Coordinator for Travellers.

### Other issues

Consultation participants raised other issues, including:

* Privacy concerns where individuals are asked about functionality as part of medical assessments (DPO contribution);
* A requirement on d/Deaf people to inform their insurance company about their disability;
* Concerns about where disability services will feature in the HSE’s new Health Regions;
* A lack of statutory entitlement to care;
* A lack of recognition by the HSE of Pathological Demand Avoidance (PDA) meaning a lack of supports to address it;
* Concerns regarding the move away from case officers in the HSE to the use of a central database;
* Concerns regarding the use of restrictive practices and behaviour-based interventions and training;
* The continued threat posed by COVID-19 to some disabled people and importance of mask wearing;
* Lack of peer support groups for people with disabilities, including adults with spina bifida and amputees;
* Difficulties obtaining a Medical Card, including long waiting times;
* Difficulties for disabled people procuring essential medication;
* Lack of dignity and privacy in hospital settings for disabled children and their parents;
* There was a perception that refugees were being prioritised on waiting lists for children’s disability services in one area;
* Lack of hospices for children and lack of palliative care teams for children;
* There was an assertion that medical professionals are refusing life-sustaining treatment because of a child’s diagnosis;
* Lack of access to specialist neurorehabilitation for children, including specialist community neurorehabilitation services;
* High consultant fees; and
* Waiting lists for orthodontic treatment.

## 5.4.2 Proposed actions and solutions

Consultation participants provided many suggestions for how challenges regarding health and social care services could be addressed in the new National Disability Strategy. Many called for the provision of timely, equitable, quality, well-resourced and well-staffed health and social care services, with particularly strong support expressed for enhanced access to children’s disability services, mental health services, and respite services for both disabled adults and children. These suggestions are listed below.

### Availability and adequacy of services

* Ensure that all disabled people have equal access to and are provided with health and social care services (contribution from DPOs and others);
* Reduce or eliminate waiting lists for health and social care services and supports (contribution from DPO and others);
* Provide health and social care services based on assessed current and future needs;
* Provide health and social care services locally;
* Ensure consistency in the provision of health and social care services to eliminate any geographic disparities;
* Provide timely access to early intervention services and supports (contribution from DPO and others);
* Foster a joined-up approach across health and social care services to ensure that disabled people do not fall between the cracks;
* Promote funding mechanisms that facilitate a holistic approach to service delivery;
* Ensure that health and social care services provide a continuum of integrated care and support to disabled people across the lifecycle;
* Increase funding for and access to multidisciplinary supports. Improve existing and create new pathways to access supports within appropriate timeframes;
* Provide more access to therapies and place a greater focus on therapeutic support and intervention;
* Ensure adequate planning for and forecasting of future healthcare needs, to include health and social care workforce and service planning;
* Develop a national roadmap for future health and social care services, based on evidence and changing demographics;
* Engage and value the contribution of disabled people in the planning and delivery of health and care services;
* Foster collaboration between government agencies and departments to improve service delivery standards;
* Ensure greater accountability and oversight mechanisms to strengthen cross-departmental working;
* Ensure that disabled people have access to publicly funded and timely assessments, including adults with a disability who may not have been assessed whilst in school, and for whom private assessments are financially inaccessible (possibly through the expansion of NEPS services);
* Introduce a legal right to services and therapy;
* Ensure that access to care and services is rights based;
* Adopt a human rights-based approach to health and social care services to support the needs of people with a disability in a more holistic way;
* Ensure that health and social care providers deliver care in a flexible and person-centred manner which is oriented to the ‘whole person’;
* Improve the provision of community health services, supports, and therapies for people with disabilities (contribution from DPO and others);
* Provide access to supplementary therapies and other holistic services;
* Provide access to comprehensive rehabilitation services, including for those with neurological conditions and those requiring cardiac rehabilitation;
* Ensure greater access to and increase the number of GPs;
* Implement the recommendations of the Disability Capacity Review to 2032;
* Avoid emergency responses and ensure service planning follows an evidence-based approach;
* Put in place coordinated agreements across the HSE’s new health regions regarding service models; and
* Ensure individualised care plans are in place for all those who require one, including plans for transitions and future care needs, and the adaptation of these plans as needs change.

### Accessibility of services

* Ensure that all health and social care services are fully accessible to disabled people and are universally designed;
* Ensure transparency of and access to information around supports and services in accessible formats;
* Ensure accessibility considerations are factored in from the service design phase;
* Ensure all public hospitals are accessible and disability friendly, including accessible wheelchair toilets, Changing Places Toilets, hoists, and automatic doors;
* Ensure funding decisions are guided by the commitment of a service to improve accessibility;
* Increase the number of health and social care professionals who use ISL and provide ISL interpreters in medical settings;
* Develop a National Hearing Care Plan to support more people, including children, to access relevant interventions such as hearing aids and assistive technology, in a timely manner;
* Improve access for the d/Deaf community across a range of critical services, such as emergency departments and counselling services;
* Oblige each healthcare provider to develop step-by-step guidelines on how to book an ISL interpreter with contact details for relevant booking agencies;
* Provide funding for existing mental health professionals to become proficient in ISL and provide training for people already proficient in ISL to become mental health service professionals, such as members of the Deaf Community, Deaf Studies graduates, CODAs etc;
* Provide funding for training courses for people to work in social care and health with the d/Deaf Community. This could be implemented through additional modules in existing courses such as Deaf Studies or Social Care degrees. Alternatively, a certificate in social care and healthcare within the Irish Deaf Community is another option; and
* Promote health education materials in ISL and culturally competent healthcare services.

### Funding and staffing

* Increase funding for health and social care services to ensure disabled people have timely and equal access to supports;
* Provide multi-annual funding to organisations providing health and social care services on behalf of the State to meet current and future need;
* Increase staffing within health and social care services to meet levels of need;
* Proactively address staff retention and recruitment issues, particularly in areas where there are critical shortages, including nursing and midwifery roles as well as roles within disability and mental health services;
* Ensure disability and mainstream health services are adequately resourced, underpinned by an evidence-based and proactive approach to planning and budgeting;
* Provide sufficient resources to implement the Disability Action Plan 2024-2026 to address the significant unmet need and future need identified in the Disability Capacity Review;
* Ensure pay parity for Section 39 organisations;
* Ringfence resources for both mainstream and targeted programmes to address the needs of people with different disabilities;
* Earmark funding for service provision based on demographic and epidemiological knowledge;
* Enable organisations providing supports and services to disabled people to spend their budget in a flexible way;
* Transform traditional service funding models to provide disabled people with personalised budgets;
* Adopt specific measures to address shortages in rural areas, to encourage young staff who might emigrate to remain and to provide access to promotional opportunities for those working within the social care sector;
* Develop a strategy to train and recruit professions into health and social care services (contribution from DPO and others). This should include measures to increase university places and expand training in areas and professions where there are acute shortages and future needs;
* Provide supports to staff to address burnout;
* Fund Section 38 and 39 organisations to recognise the ‘previous experience’ of social care staff to reduce reliance on agency workers;
* Do not oblige organisations applying for Section 39 funding to make a business case;
* Provide adequate funding and greater streamlining of the approval system to fill vacant clinical posts, including in mental health services;
* Provide access to specialised health professionals where necessary;
* Ensure accountability and monitoring of expenditure of budget allocations on disability services by the HSE and voluntary organisations;
* Link decisions on funding to efforts to improve service delivery and outcomes;
* Underpin the Framework for Safe Nurse Staffing and Skill Mix by legislation and extend this framework to the community and intellectual disability sector;
* Incorporate a child rights-based approach to the budgeting process, including by defining specific budget lines for all children, paying special attention to children with disabilities;
* Develop a financial input and output model of the funding of the disability services sector;
* Oblige charities to share their money directly with disabled people; and
* Conduct a study on the link between symptoms of trauma and the high turnover of staff in social care services.

### Cross-cutting issues

* Provide more accessible information regarding health and social care services and better signposting towards supports. Suggestions included the development of a central database for all services, the appointment of a key worker to families and the designation of a centralised contact point to coordinate the delivery of services;
* Provide prompt access to HSE aids, appliances, and assistive technology;
* Ensure that health and social care professionals understand and are aware of the diverse needs of disabled people;
* Ensure health and social care professionals speak directly to disabled people and not their supporter;
* Ensure the availability of proper IT infrastructure, unified electronic health and social care records and eHealth services;
* Improve access to independent advocacy services to enhance engagement with health and social care services;
* Ensure health and social care services have effective complaints systems that are accessible to all;
* Ensure that mainstream health services are disability inclusive;
* Centre the strategy on Sláintecare commitments, focusing on timely accessibility, improved community care quality, and the provision of multidisciplinary therapies (DPO contribution);
* Develop a common information system across health and social care services;
* Adopt a human rights-based approach to health and social care data, including transparency regarding how and why data is collected, used, and shared;
* Oblige service providers to inform people with disabilities how they keep their personal information safe;
* Provide disability training, led by disabled people, to health and social care staff, covering topics such as the social model of disability, human rights responsibilities, the new supported decision-making arrangements, and hidden disabilities;
* Ensure that disabled people are treated equally and do not experience discrimination when accessing health and social care services;
* Optimise the role of the Registered Nurse in Intellectual Disability to a greater extent in both specialist and mainstream health and social care settings;
* Overhaul or reform the HSE to meet the needs of people with disabilities by amalgamating Section 38 and 39 organisations and carrying out regulatory reform to address competing regulatory processes;
* Ensure that health and social care services draw from international expertise and best practice, consistent in quality and efficient;
* End the use of certain behaviour-based interventions, training and therapies that some people believe contravene the rights of autistic people.
* Ensure that restrictive practices are only used as a last resort;
* Provide individualised care to service users;
* Improve the governance of the Health Service Executive; and
* Move away from repeated pilots of programmes.

### Disability services

* Improve access to and increase funding for disability services. Disability services should be demand-led rather than resource-led;
* Ensure that staffing levels within disability services allow for more individual supports rather than group activities;
* Modernise and reform disability services towards a user-led approach in the way services are designed, provided, and monitored;
* Ensure sufficient and safe staffing and skills mix in disability services;
* Locate disability services in accessible buildings in the community;
* Allocate funds to disabled people to enable them to choose services through personal budgets and creative community-based models of support;
* Address the ‘funding crisis’ in disability services and develop a roadmap for engaging with disability service providers on this issue;
* Strengthen the focus on culture change from the ‘care’ model to the ‘support’ model and deliver a model of disability services that supports empowering people to make decisions in their own lives;
* Ensure that disability services are robust and continue to be person-centred by adapting to the changing needs of individuals;
* Expand the delivery of multi-disciplinary supports within disability services;
* Review the ‘Transforming Lives’ policy to ensure that it aligns with the UNCRPD and incorporate learnings since its introduction;
* Facilitate easier navigation of disability services;
* Make greater use of the skills and knowledge of nurses and midwives within disability services; and
* Ensure the state directly provides all disability services.

### Day services

* Increase staffing levels in day services to support people to achieve their personal goals, undertake individualised activities and participate as much as possible in their communities.
* Staffing hours in day services should be flexible and staffing levels should also facilitate activities in the evening and short breaks and holiday;
* Ensure that day services are accessible and located in the community, that activities are community based and maximise choice, and that private transport is available;
* Guarantee a day service placement to any disabled person who may want one;
* Increase one-on-one time with key workers;
* Inspect day services to ensure adherence to the New Directions policy and ensure accountability for service delivery;
* Review the New Directions policy; and
* Reform the model of day service provision.

### Respite services

* Increase the provision of respite services for both adults and children with disabilities;
* Provide regular and consistent access to respite support;
* Increase the number of children, adults and families availing of family-centred supports (which can be alternatives to respite);
* Ensure greater choice in respite service provision, including residential and home-based respite; and
* Increase PRSI contributions by 0.5% to cover the costs associated with additional respite services.

### Residential care services

* Provide access and a pathway to residential care services;
* Locate residential care services in the community;
* Revoke any house rules which deny disabled people the ability to have meaningful relationships;
* Ensure residential care staff can drive so that residents can get out and about;
* Ensure staffing levels are sufficient to provide one-on-one support to people with disabilities;
* Promote greater oversight of residential services, including by HIQA and the Mental Health Commission;
* Undertake a review of the regulatory framework governing residential services, to include formal engagement with a variety of stakeholders, such as people with disabilities and their representatives;
* Commit to accelerated implementation of the recommendations in the Ombudsman’s ‘Wasted Lives’ report;
* Commit to no longer admitting young disabled people (under 65s) into nursing homes;
* Undertake urgent planning to ensure an adequate supply of long-term nursing home care beds to cater for older people with disabilities; and
* Provide those in residential care with greater choice over who shares the accommodation.

### Children’s disability services

* Provide timely access to therapies and services to all children who require them on an ongoing basis, including physiotherapy, speech and language therapy and social work support;
* Ensure that children’s disability services are fully staffed and adequately resourced and that children have greater access to the specialised supports available through Children’s Disability Network Teams;
* Improve early intervention services and supports for disabled children (contribution from DPO and others);
* Provide early intervention services through timely and holistic assessments of need;
* Ensure the HSE provides assessments of need within the statutory timeframe and reduce waiting lists for assessments;
* Embed a human rights-based and child-centred approach to Assessment of Need in line with the Ombudsman for Children’s ‘Unmet Needs’ report;
* Review the assessment of need process;
* Abolish the entire assessment of need process as ‘it is pointless and gets you no services’;
* Undertake a review of service provision under the Progressing Disability Services for Children and Young People programme;
* Undertake a review of the supervision and clinical operation structures in children’s disability services;
* Implement the Roadmap for Service Improvement: Disability Services for Children and Young People 2023–2026;
* Establish a legal entitlement to state-funded diagnostic services and ongoing therapy interventions;
* Increase child and parent satisfaction with access to CDNT services (to be measured through survey data);
* Propose that health professionals within CDNTs limit their caseload size;
* Revise and resource the HSE’s Autism Action Plan;
* Provide a range of supports to meet the needs of children with an acquired brain injury, including the development of paediatric specialist neurorehabilitation services and a pathway of transitional care for children moving from paediatric to adult services;
* Ensure equality of treatment for disabled children and listen to the voices of young people regarding their needs;
* Guarantee an integrated, child-centred and joined-up approach to the delivery of services for disabled children, including a system for the appropriate sharing and management of information;
* Establish clear referral and care pathways for children’s disability services and develop care plans which specify the organisation responsible for providing services;
* Appoint key workers to families;
* Do not make children and young people, and their families, travel long distances for specialist supports;
* Foster greater cooperation between healthcare and educational services, including on therapeutic supports in schools and care and supports during the summer holidays;
* Improve transition planning from children’s disability services to adult services (contribution from DPO and others). Ensure transition planning is timely, that it includes communication between children’s and adult services, and increase the number of social workers to facilitate smooth transitions;
* Provide supports for disabled children and young people to stay healthy and active, courses on eating more healthily, opportunities for travel, and opportunities to have relationships or get married; and
* De-politicize the provision of services for children with disabilities.

### Home care services

* Increase the provision of home care services;
* Ensure disabled people have regular, consistent, and adequate access to home care support;
* Provide more intensive home support packages, including support at an earlier stage; and
* Undertake a review of home care services, with one consultation participant suggesting that some people with certain disabilities could be better supported to exercise choice and care for themselves.

### Child and Adolescent Mental Health Services (CAMHS)

* Provide more mental health and counselling supports to children;
* Ensure equal access to timely mental healthcare for children;
* Increase CAMHS staffing and resources and ensure greater availability of CAMHS supports, including through a reduction in waiting lists and times;
* Reform and overhaul CAMHS, with one submission recommending that the strategy commit to implementing the Mental Health Commission’s 49 recommendations to reform CAMHS;
* End the unequal treatment of autistic children and children with intellectual disabilities seeking access to CAMHS services;
* Introduce a transparent complaints process for CAMHS;
* Appoint a keyworker to all families accessing CAMHS;
* Develop a care plan for all children accessing CAMHS;
* Deliver on the commitment to provide out-of-hours mental health treatment for children;
* Provide greater transparency around the CAMHS criteria for acceptance of referrals and consistent application nationally;
* Increase and fully staff CAMHS-ID;
* Ensure that Registered Nurses in Intellectual Disability are a key part of CAMHS teams;
* Provide training to teachers and parents on mental health issues, including neurodivergent children with mental health issues;
* Ensure annual ring-fenced funding for CAMHS;
* Establish a d/Deaf CAMHS;
* Identify and implement other models for the delivery of mental health services for children;
* Set benchmarks for CAMHS staffing nationally and develop clear action plans on how these targets will be met and maintained;
* End the practice of discharging (or threatening to discharge) children whose families decide not to use medication or take part in a parenting course recommended by CAMHS professionals;
* Ensure proper provision for those with eating disorder services and gender and sexuality services; and
* Improve the provision of information to and communications with families concerning the mental healthcare of a child.

### Adult mental health services

* Enhance access to mental health services and provide greater mental health supports for disabled people;
* Increase funding for mental health services, including through implementation and adequate resourcing of the Sharing the Vision policy;
* Promote trauma informed mental healthcare;
* Provide person-centred mental health services which respond to lived experience (DPO contribution);
* Fund stigma reduction campaigns;
* End discrimination in the provision of mental health services;
* Ensure that people with disabilities have access to appropriate specialist psychological support;
* Develop a Mental Health Service for the d/Deaf community;
* Increase the number of d/Deaf therapists;
* Provide funding for existing mental health professionals to become proficient in ISL and provide training for people already proficient in ISL to become mental health service professionals;
* Provide adequate funding for mental health services for adults with intellectual disabilities;
* Ensure that mental health services can screen, identify and are inclusive of those who are neurodivergent;
* Ensure that people with a psychosocial disability are a key consideration in the strategy; and
* Provide appropriate mental health supports to amputees.

### Supports for adults and children with autism

* Ensure that the diverse needs of autistic adults and children are met with appropriate, age-sensitive service provision;
* Build an understanding of the needs of autistic adults as they age and how that differs from a non-autistic adult;
* Expand the public assessment and support system so that children and adults seeking autism assessments and subsequent supports do not experience significant waiting times or resort to private services;
* Provide mechanisms to ensure the essential and mandatory provision of diagnostic and services pathways, underpinned by sufficient resources;
* Ensure adults have access to autism and ADHD assessments;
* Recognise Pathological Demand Avoidance (PDA) and provide specific supports for individuals with PDA; and
* Revise and provide additional funding to the HSE’s plan for autistic children.

### Hospital care

* Increase resources for hospitals;
* Ensure hospitals are disability inclusive and accessible, including through the availability of Changing Places facilities, automatic doors, hoists etc.;
* Provide appropriate supports and facilities to the parents and carers of adult children in hospital, including a bed, and allow adult patients to be supported by their carer when they are receiving treatment in hospital;
* Provide nutritious food to those in hospital;
* Overhaul care in hospitals to better meet the needs of disabled people;
* Ensure that disabled people are not left on trolleys or in ambulances while waiting to access emergency services;
* Improve access to hospital services and emergency care, including surgeries and scoliosis treatment;
* Consider the needs of an individual child, not their age, when deciding whether to transfer them from a children’s hospital to an adult hospital;
* Provide appropriate information on supports in the community following discharge from hospital; and
* Increase the number of disabled patients on hospital boards, including those with rare conditions.

### Neurology services

* Include a commitment to implement and resource the National Strategy and Policy for the Provision of Neurorehabilitation Services in Ireland, From Theory to Action, Implementation Framework 2019-2021;
* Include a dedicated section with the strategy on neurorehabilitation;
* Re-orient the healthcare system from hospital to primary care community services in line with Sláintecare commitments and invest in specialist neuro-rehabilitation services in the community;
* Roll out and expand the availability of properly resourced neurorehabilitation services around the country;
* Ensure commitments to the development of neurorehabilitation services outlined in the Action Plan for Disability Services 2024-2026 are actioned within the timeframe of the new strategy;
* Make full provision for the long term needs of people living with a neurological disability throughout Ireland, to include individuals living within long-term care facilities; and
* Increase the number of residential rehabilitation beds to meet current and projected need and spread availability of these beds proportionately around the country.

### Intersectional groups

* Promote greater links between disability services and local Traveller organisations with a view to identifying and ensuring appropriate follow up care for Travellers with disabilities;
* Address mental health issues within the Traveller Community;
* Put in place affirmative action policies to employ Travellers within disability services;
* Ensure quicker referrals to CAMHS for Traveller children;
* Increase funding to Traveller organisations to provide supports to Traveller children with autism;
* Provide more resources and supports for d/Deaf Travellers;
* Recognise the unique mental health challenges faced by disabled LGBTQI+ individuals and prioritise mental health supports for them, particularly for the trans community;
* Allocate resources for the provision of targeted mental health support services that address the intersectionality of disability and LGBTQI+ identity. This may include counselling services, peer support groups, and awareness campaigns that specifically cater to the needs of this demographic;
* Provide training to healthcare staff on LGBTQI+ and intersectional issues; and
* Address the need for supports, services, and inclusion for the increasing number of disabled refugees and people with disabilities seeking international protection.

### Other recommendations

* Recognise end of life care as a vital part of the healthcare system and resource it accordingly. Hospices should not have to fundraise continuously;
* Develop measurable outcomes for services and ensure disabled people have meaningful input in establishing such outcomes;
* Allocate a social or support worker to disabled people and remove barriers preventing disabled individuals from accessing social services;
* Add the chicken pox vaccine to the childhood vaccine schedule;
* Ensure that disabled children do not experience discrimination, medically, on the grounds of their disability, diagnosis, or life expectancy. The medical system should not have the authority to judge ‘quality of life’ or what constitutes a ‘life limiting condition’;
* Provide tube feeding supports, research rare diseases and test newborns for rare diseases;
* Increase empathy and understanding shown by visiting healthcare professionals i.e., recognition that they are entering a home, not a place of work;
* Address the challenges faced by people living with disabilities in terms of lower health levels, increased rates of depression, and reduced physical activity;
* Proactively address the effects of alcohol, gambling, and other addictions on disabled people; and
* Reduce waiting lists for the medical card.

# 5.5 Independent living

## 5.5.1 Context and challenges

Throughout the consultation, DPOs and other consultation participants called for better supports to live independently and be part of the community. They expressed frustration with existing funding models for personal assistance and highlighted barriers to social inclusion, including accessibility. Persons with disabilities stressed the need to end congregated settings. It must be recognised that accessibility (including built environment, communication, information and assistive technology) access to transport, housing, culture, leisure, recreation and sport all play an essential role in facilitating independent living. These topics are discussed within other sections.

Participants identified choice, control and support as key factors in achieving independence and community participation. People with disabilities sought freedom to achieve their goals, including to move house, to spend time with friends, to travel, to explore their sexuality or parent their child. As one survey respondent explained:

‘I am a single father (…) I do not have the freedom to move around bring my child to any parties or any educational things that may be happening or sport things (..) I have no access to transport or anyone like a PA to bring me.’

One written submission shared in the disappointment of the Joint Committee on Disability Matters at the perceived lack of progress in terms of people with disabilities living in an inclusive community, with this organisation feeling the situation had even regressed. It was stated that no-one should be obliged to live in a residential setting due to lack of support. Consultation participants emphasised the importance of being happy with one’s living arrangements. Children placed value on being able to make their own decisions and to learn by experience. Bureaucracy was identified as a barrier to active citizenship. Consultation participants called for future-focused planning and funding for HSE assessments of need. As one survey respondent described:

‘We have no plan I do not want to live with my parents all my life; it is my life I want to decide how I live it.’

Consultation participants called for a flexible, person-centred approach, with early intervention for young adults with intellectual disabilities; they felt it was important to make a timely transition to supported independent living. It was noted that this must take place in an ordinary home, not a ‘unit’. One carer described the time-sensitive nature of the situation in their survey response:

‘As an aging parent my child is going to have the grievance of losing his parent and home at the same time. This is unacceptable!’

### Personal assistance

Consultation participants highlighted issues with the current for-profit model of personal assistance (PAs), the reality of which relegates PAs to caring and undermines the independent living philosophy (whereby disabled people are empowered as ‘leaders’ to direct PAs in their duties, supported to lead full lives and participate in the community). Many problems were reported to stem from a lack of funding, including insufficient, inflexible hours, staff shortages, and a lack of contingency planning. For instance, a participant with high support needs noted that they were forced to pay for additional personnel to accompany them outside the home.

People with disabilities emphasised the need for recruitment and retention within the industry, calling for better pay and expenses, especially in rural areas. A participant in one focus group stated:

‘I’ll have to leave at 7.45pm as my care hours dictate my bedtime (…) If HSE are awarding care to agencies they need to enforce that in the agencies – that agencies are flexible (…) The agencies need to be paying commensurate with the HSE. You need your care staff to enjoy their job. It goes back to respect and valuing people’s job. I value the people that help me.’

There was a sense that many people in need of PAs were surviving rather than thriving. These participants acknowledged having unmet needs but were reluctant to ‘rock the boat’ in case this risked a reduction in their existing allocation.

Consultation participants argued that access to support must not be limited to medical or educational needs but expanded to include employment or recreational activities. One submission explained:

‘PA hours are used to get me up and to bed, as a person I’m much more than that.’

Carers emphasised their willingness to engage with the new Assisted Decision-Making Capacity Act as decision-making representatives or co-decision makers, supporting family members with complex needs to direct PAs. They were frustrated with the system which is means-tested and resource-led, rather than needs-based.

Older people felt they were being infantilised due to PA shortages/inflexible hours. This group of people with disabilities also expressed concern that they were being pushed back towards institutionalisation by a lack understanding of independent living as a more cost-effective alternative to nursing home or hospital care.

A member of the LGBTQI+ community explained that they would not engage with a home care provider for fear that the PA would not accept their gender identity or sexual orientation.

### Finances

Consultation participants pointed out that that perceived incapacity/vulnerability can lead to problems accessing financial services and taking control of one’s own money. It was noted that the cost-of-living crisis has meant some people with disabilities increasingly have to limit or sacrifice leisure and recreational pursuits and community activities due to limited funds. Consultation participants expressed frustration with the low rate of Disability Allowance, which left them with little money for discretionary spending in comparison to non-disabled peers. One consultation participant stated:

‘Other people would spend what we get a week on their dinner out… I think if the Government had to live on what we live on a week they’d give us more.’

### Personalised budgets

A DPO noted that there needs to be a consideration in the strategy of an individual’s rights and agency to make their own financial decisions. Other consultation participants were concerned with the lack of progress on personalised budgets in Ireland, despite the publication of ‘Towards Personalised Budgets for People with a Disability in Ireland’ in 2018 and the initiation of a demonstration project in 2019. A submission noted concerns about the pace and limited scope for learning about national implementation of this demonstration phase. Another consultation participant felt the Irish approach to personalised budgets is problematic, in that to date it has been about funding for services people already receive, not what is actually needed. The Australian National Disability Insurance Scheme was cited as good practice in relation to personalised budgets.

### Transitioning from congregated settings

Consultation participants urged the government to listen to people with disabilities about where and with whom they wish to live. There were concerns about the significant numbers of people still residing in congregated settings. There were calls to expedite the transition process and provide community-based services, including for disabled people under 65 years who are living in nursing homes. People with mental health difficulties were keen to remind peers in hospital settings that transition to the community is possible, with the necessary step-down support. It was explained that people with disabilities faced uncertainty in the wake of hospital discharge, fuelled by a lack of supports and high staff turnover. They stressed the importance of being able to establish a relationship with one’s home care provider. The potential for alternative living arrangements e.g., home sharing was also noted. Consultation participants emphasised that the transition to the community has led to huge improvements in safety and quality of life for people with disabilities.

### Social inclusion and wellbeing

Many consultation participants experienced social isolation and diminished wellbeing (especially poor mental health) as a result of limited community participation. Peer support was recognised as a protective factor, the absence of which can exacerbate existing mental health conditions. Questions were raised about how the over-arching impact of the exclusion experienced by disabled people could be captured within the strategy:

‘The social isolation is a human cost, the cost of trauma, our pain is another cost. Are these factored in this document?’

In one example, an older disabled person reflected on the failure of Local Community Development Partnerships to accommodate disability, costing them social connections:

‘They *[partnerships]* have a brief around older people for the partnership, are they sticking to that brief (…) I would question the funding and how it is being used, is it being used the same as the department idea, which is different to what people are living on the ground. I feel totally isolated from my community.’

A DPO identified older Deaf people and those living in rural areas as being more likely to lack connections with other Deaf people. They also noted that Deaf young people experience a “culture shock” when they transition to university and stressed that more action is needed to secure their future.

## 5.5.2 Proposed solutions and actions

Consultation participants provided many suggestions for how challenges regarding independent living could be addressed in the new National Disability Strategy. These include reviewing existing standards, prioritising ongoing commitments with regard to personalised budgets, and developing a national plan to realise the right to live independently within domestic policy and legislation.

### Personal assistance and support

* Ensure that the Personal Assistance Service (PAS) is defined, standardised, resourced, promoted, legislated for, and separate from other home care supports;
* Implement and fund a proper PAS with greater hours, determined by the disabled people themselves;
* Establish a liberal system of self-directed support, which allows disabled people to employ whomever they wish, without being limited to paying supporters by the hour (DPO contribution);
* Make PA available to every disabled person in Ireland;
* Provide PA to children and young people to be more independent and access their communities without their parents;
* Review criteria for PA hours to ensure it is based on need not on diagnosis;
* Improve access to PA for people with disabilities who live at home to take part in weekend activities;
* Increase the number of people with intellectual disabilities availing of PA;
* Increase available PA hours to go beyond completion of everyday tasks to support engagement in public and social life. Review perceived impact on unmet needs/individual autonomy;
* Provide the resources so that every person with a disability is able to create their own roadmap, while remaining safe in the knowledge that their supports will not be taken away; and
* Provide resources and support over the life course to help disabled people achieve their goals.

### Finances

* Ensure financial stability and continuity of support for disabled people.

### Personalised budgets

* Implement the recommendations of the Taskforce on Personalised Budgets. Consider how the current demonstration phase can be concluded to inform next steps as a matter of urgency;
* Introduce personalised budgets to individuals on a national, permanent basis, based on any learnings from the demonstration phase and from the extensive learning available in other jurisdictions;
* Employ experts with lived experience to train and assist people in getting the most from their personalised budgets;
* Provide targets for the additional allocation of personal budgets to ensure that people with disabilities can lead self-directed lives outside of traditional, residential arrangements.
* Provide personalised budgets in accordance with the assessed support needs of disabled people who want their own budget;
* Increase the funding available for personalised budgets enabling child/adult and family-centred, community-based, supported living to ensure that people with disabilities can lead autonomous lives in a home of their choice; and
* Transform services to better allow the allocation of funds to beneficiaries and their advocates/ families through personal budgets and creative community-based models of support.

### Transitioning from congregated settings

* Meet annual targets for people moving out of congregated settings commencing with areas where there are identified human rights issues;
* Review National Standards for Residential Services for Children and Adults with Disabilities, with reference to the UNCRPD and ADM Act;
* Change the expectation that people with intellectual disabilities should have to live in group homes. Respect the agency, choice, and autonomy of each individual in planning for their lives;
* Review HSE’s Time to Move on From Congregated Settings.’ Develop a new, time-bound implementation plan;
* Expedite the transition of people with disabilities from congregated settings to communities. Limit reliance on emergency residential placements;
* Plan and fund the exit strategy for young people in nursing homes; and
* Provide suitable accommodation and supports in the community.

### Support independent living

* Introduce a mentor/buddy system enabling young people seeking peer support to try out new places and activities in the community;
* Explore options for peer or mutual support, provided by people with disabilities for other people with disabilities e.g., learning ISL, befriending, supporting independent travel/road safety;
* Provide opportunities to trial independent living;
* Improve access to home help or care services to promote independence and reduce reliance on family members for personal care;
* Facilitate the learning of independent living skills e.g., cookery, self-care from an early age;
* Prioritise legislating for the right to live independent lives, over legislating for the option of assisted suicide;
* Develop a national plan to realise the right to independent living as part of the over-arching policy framework. Support agencies to reconfigure their services accordingly; and
* Ensure equity of expectation for those with high support needs living with family to have a home of their own as per will and preference.

### Other issues

* Recognise inflationary pressures and rising service costs for community organisations.
* Explore options for the development of intentional communities where people with MS can live independently with appropriate support;
* Widen existing regulations beyond Assistance Dogs International (ADI) accreditation to allow more people with disabilities to access assistance dogs;
* Promote social prescribing and inter-departmental cooperation (DPO contribution);
* Fund organisations which have a track record of delivery on community and rights-based approaches;
* Strengthen the national broadband network to ensure that people with disabilities in rural areas can access resources for education and personal development;
* Employ a whole of government approach to providing supports based on individual need e.g., housing, transport;
* Ensure that people whose legal capacity is in question have timely access to the Decision Support Service and independent advocacy;
* Support people with intellectual disabilities to make decisions and get the information they need to do so;
* Ensure people with disabilities have access to a range of in-home, residential and community supports to prevent isolation and segregation;
* Enable charities to pool and share funds directly with disabled people, to facilitate a life of dignity, freedom, and choice; and
* Implement all recommendations from the final report of the Oireachtas Joint Committee on Autism.

# 5.6 Housing

## 5.6.1 Context and challenges

Throughout the consultation, participants, with some input from DPOs, called for accessible, affordable housing for disabled people. They expressed dissatisfaction with current levels of available social housing and the bureaucracy surrounding applications for grants and entitlements. The housing crisis for people with disabilities was characterised as a ‘disaster within a disaster.’ A carer urged consideration of what it really means to let people live longer in their own homes and argued for better recognition of what that home looks like and what families may need.

### Accessible housing

Consultation participants highlighted the urgent need for more accessible housing. Many indicated that they were living in accommodation that failed to meet their needs and was not fit for purpose. One participant highlighted the difficulty of the planning permission process for building an accessible private property, while another participant with a visual impairment who owned their home noted there was no one to oversee their home renovations by private tradespeople: ‘they could literally rob me blind’. The shortage of universally designed homes was identified as a significant barrier to independent living and ageing in place. One consultation participant added: ‘If you are looking for something accessible, they just don't exist.’

Consultation participants suggested that the government has failed to accelerate investment in building accessible housing and that this has resulted in disabled people being unable to avail of Housing Assistance Payments (HAP), social housing, or rent-to-buy schemes. They felt it was important to live in communities with accessible infrastructure and local amenities, including public transport.

### Available housing

It was reported that there is a lack of new housing developments in Ireland which are inclusive of people with disabilities. Consultation participants felt that the housing shortage has left disabled people at a disadvantage within the competitive rental market, with nowhere to go if properties were sold. One survey respondent stated:

‘I was very lucky to have found this ground floor, barrier free apartment and have been in it for the past decade, but I am always in a precarious situation.’

In terms of social housing, consultation participants noted complicated forms (no Easy Read versions) and extended waiting lists, with a shortage of one-or-two bed homes. It was highlighted that one can become stuck in transitional housing or community residency, despite being ready to move on, due to the social housing shortage. Issues were flagged with the system whereby people with disabilities who move to a new local authority area must begin a new application, starting all over again at the bottom of the list. A written submission stated there was a lack of understanding of disability issues within local authorities (including communication needs). They argued that offers of social housing did not take account of location or proximity to natural supports such as family and friends, with disabled people perceiving themselves to be under pressure to accept inappropriate accommodation for fear of being removed from the housing list.

Concerns were raised about discrimination by landlords, specifically the risk of being refused rental accommodation due to disability e.g., guide-dog users excluded by a ‘no pets’ policy. There was a call for tenancy sustainment supports to help individuals who would otherwise be at a higher risk of eviction - e.g., learning household management skills such as paying bills. Some participants also noted issues with joint tenancy. Children with disabilities were conscious of the housing crisis and how it may limit their options as they enter adulthood. They felt it was important to have their own space within an adapted house.

### Affordable housing

Consultation participants strongly felt that ‘affordable housing’ remains far out of reach for many disabled people. There was a sense that many people were falling through the gaps; those who did not meet social housing criteria still did not have the means to build or purchase a private house and were priced out of an inaccessible rental market.

It was noted that the Housing Assistance Payment (HAP) was insufficient. Consultation participants felt that local authority flexibility to go up to 35% above HAP rent limits does not go far enough in the current crisis, when rents can be up to half of one’s income. One example saw a carer on long-term Carer’s Allowance frustrated that their income was not recognised for a mortgage, while another survey respondent detailed the failure of eligibility criteria or income thresholds to account for individual needs. One consultation participant stated:

‘The nature of my disability means shared housing is not appropriate for me. However, despite working in a "good" job and earning close to the median wage, I cannot afford to live alone even in a one room bedsit. I am technically homeless (sleeping on a relative's couch) due to the lack of financial or housing supports.’

### Impact on wellbeing

Consultation participants identified the negative impact on their lives of housing uncertainty, such as frequent moves or threat of eviction. There was an emphasis on the need for stability and safety, for a place to call home. A connection was made between the quality of housing and the rate of disabling/chronic conditions such as asthma. In one example, a participant was unable to receive fuel allowance or a household benefits package due to living in shared accommodation. The financial pressure took a toll on their mental health and led to a subsequent overdose, which has resulted in homelessness. They stated:

‘I am now of no fixed abode but will not enter the hostel/homeless scheme because it is dangerous (…) I have been assaulted multiple times (…) Homelessness is not safe for disabled people!’

### Intersectionality

Consultation participants from marginalised groups highlighted unique challenges faced by their communities, including specific issues for Travellers with disabilities. There was an acknowledgement that halting sites are designed in a generic way and often poorly located. There were calls for the Department of Housing to issue guidelines for the design of Traveller-specific accommodation which is sensitive to the needs of people with disabilities.

Participants highlighted that there can be difficulties and delays in getting mobility equipment e.g., hoists installed for those living in mobile homes. Local authorities were requested to reach compromises with Traveller families who had met with refusals to adapt housing and failure to provide resources to access aids such as in-home oxygen.

Asylum seekers with disabilities stated that their housing needs were not met within direct provision centres. An asylum seeker from one focus group explained the challenges of transferring accommodation and recalled being forced to share inaccessible facilities with many others:

‘When I first transferred to [direct provision accommodation] –sharing a room with 6, sharing bathroom with 25 – I had to sit on the ground in the shared bathroom (…) HSE had to request for a room – I have a room of my own now– it is still not accessible but I have my own bathroom.’

Asylum-seeking consultation participants stressed the negative impact on their mental health and wellbeing, with families sharing confined spaces for an extended period. This was identified as an issue for an autistic child (at risk of escape to play outside) and a disabled adult (at risk of bumping into objects or falling over due to lack of space).

### Housing strategies

There were major concerns about the sheer number of recommendations within existing national housing strategies, such as the National Housing Strategy for Disabled People 2022-2027. Consultation participants were frustrated by the slow progress within housing disability steering groups. They argued strongly for a stripped back approach, with targeted actions and a higher percentage of suitable accommodation (including wheelchair liveable homes) within social housing. A consultation participant commented on the situation in general:

‘We can talk all we can in relation to these discussions about strategies and action points, but if we don't actually get the actions to happen it's just more paper.’

### Issues with housing applications, grants, benefits and entitlements

The Housing Grant for People with a Disability was declared in urgent need of reform. Consultation participants raised concerns about the means testing (as it applies to the household, not the individual) and the discrepancy between the level of funding available in comparison with the cost of necessary works, especially for working families. Disabled people felt it was unfair that the grant covers the installation of equipment and aids, but not architect/engineer fees or fittings. Participants also felt it unfair that the grant is halved for houses under 12 months old. Similarly, consultation participants highlighted issues with eligibility criteria for the grant, including only being able to apply for the grant when you’ve built to wall plate level and the lengthy appeals process if refused.

Members of one focus group pointed out that the high level of bureaucracy and rigorous means testing prevents those with newly acquired impairments from qualifying for the grant based on the previous year’s earnings, hindering them from adapting their home in a timely manner. It was understood that there is wide variation across the country in the timeliness of the process, leading to a ‘postcode lottery’ in how long an individual is waiting to access funds. A consultation participant flagged that applications for the Capital Assistance Scheme cannot be submitted without HSE commitment to provide supports, which is impossible due to the lack of multi-annual funding.

## 5.6.2 Proposed actions and solutions

Consultation participants proposed a variety of actions and solutions to address housing challenges within the National Disability Strategy. These include designating new duties to existing agencies, expanding criteria for the allocation of housing supports, and measures to improve uptake of private rental accommodation or home ownership by persons with disabilities.

### Accessible housing

* Amend Building Regulations 2010 Part M to mandate a minimum percentage of wheelchair liveable dwellings;
* Increase the number of newly built universally designed housing stock by setting a target in terms of percentage/year e.g., 30% by 2030;
* Designate an agency to oversee in-home renovations for disabled people (including visually impaired people) who own private property;
* Review housing regulations in consultation with DPOs to update minimum requirements for accessibility in rented accommodation; and
* Provide an initial assessment to immediately identify the housing needs of migrants with disabilities.

### Affordable housing

* Increase Corporation Tax to fund housing for all. Introduce a 1% tax on house sales nationally to fund community living for disabled people;
* Remove the legal obligation to have mortgage protection insurance, including by the Local Authority Home Loan;
* Increase social housing stock. Widen the income threshold eligibility cut-off point for people with disabilities or chronic illness;
* Expedite the Housing Adaptation Grant applications of those with newly acquired impairments insofar as possible, to support discharge from hospital or rehabilitation centres; and
* Publish the Review of the Housing Adaptation Grant. Develop wider spending criteria (including engineer/architect fees) and a higher means testing threshold which accounts for future earning capacity, alongside the previous year’s income.

### Available housing

* Ensure that any public investment to address the housing crisis is fully inclusive of the needs of disabled people (DPO contribution);
* Implement protections for disabled people disproportionately affected by unsafe housing conditions;
* Implement non-discrimination policies to uphold the rights of people with disabilities and end exclusionary housing policies;
* Prioritise the availability and allocation of different housing options for people with disabilities on the basis of need. Invest in social housing which meets the needs of those with a variety of impairments; and
* Allow for transfer of social housing applications, with the allocation of a similar place on the new list (pending review) if a person with a disability must move to a new local authority.

### Cross-cutting issues

* Implement a whole-of-government approach to housing through strategic planning, open dialogue with key stakeholders, resource development and policy interventions which result in real change in disabled people’s lives;
* Mandate that local authorities provide regular updates to people with disabilities on the social housing application process;
* Hire a dedicated housing advisor within each local authority to encourage disabled people to apply for social housing. Ensure that posts within local authorities which have a housing and disability remit can be filled externally, by suitably qualified candidates;
* Mandate the provision of services such as home maintenance/repairs to people with disabilities who have bought their property from a local authority (DPO contribution); and
* Implement joined-up services with HSE and local authorities to ensure that social care needs are provided for in tandem with housing needs. Provide links with social workers.

### The National Housing Strategy for Disabled People 2022-2027

* Reinforce existing action points within the National Housing Strategy for Disabled People 2022-2027;
* Improve monitoring of the housing strategy in sync with the capacity review action plan; and
* Review the function of the housing and disability steering groups.

### Specific groups

* Address the low uptake of social housing and independent living supports by people with intellectual disabilities by setting regional targets; and
* Gather disaggregated data to ensure that people with complex needs are not left behind. Plan for long-term housing needs rather than waiting for emergencies to happen.

# 5.7 Education and training

## 5.7.1 Context and challenges

Across the different consultation activities, participants suggested ways to address challenges and barriers to education and training for disabled people. Participants contributed recommendations on ‘Education’ (i.e., education as an ongoing process) a lot more than ‘Training’ (i.e., training opportunities for specific reasons/skills). Challenges in school settings (i.e., primary, and post-primary) were raised much more than in pre-school, third level or further/adult education contexts.

Although many areas came up across the consultation, the major issue raised by participants was the need for more support and resources for inclusive education practices. For instance, an example of a typical survey response about changes participants want to see in education settings was - ‘Education supports. Inclusion is not inclusion without support’. At times, participants contrasted education and training in Ireland to other countries; as one focus group participant said, ‘If a disabled person is in the UK, they have more options re training and certification, be it catering, literacy, numeracy’.

Some of the unique contributions from DPO representatives centred around general approaches and principles to improving education for disabled people (see subsection below - general approaches and principles to improve education for disabled people). DPOs were typically more critical of the current education system, as seen in one DPO submission in a call for more evidence-based practice:

‘There is no evidence that supports the current education system for people with disabilities. The education system in Ireland requires a drastic overhaul to enable people with disabilities to engage and progress.’

### Capacity of education systems for inclusive education practices

Across the consultation, in general, participants supported moving away from special school settings towards inclusive education practices within mainstream school contexts. However, they said this transition requires collaboration between many actors and that children’s voices should be at the centre. Consultation participants reported barriers and challenges involved in building capacity of mainstream systems for inclusive education practices across a range of areas. For example, one submission highlighted:

‘What is accepted for disabled children and young adults would not be accepted for non-disabled children (e.g applying to multiple schools, travelling long distances to school, reduced timetables, lack of accommodations in the school environment, lack of ambition for children’s education)’

#### Support and resources for inclusive education

Many participants reported that appropriate supports and resources for inclusive education are not available in mainstream education settings. As one survey respondent said, ‘schools need to be provided with adequate resources to make education accessible for people with a disability and not simply lip service provided’. A DPO representative said the strategy ‘must look at how special class supports can be facilitated within a mainstream environment and ensure that practices are put in place to ensure that every child can be included in their local school’. Parents, for example, talked about the stresses of fighting for places in appropriate schools. Disabled university students highlighted how they are missing out on education due to a lack of control over personal assistance (PA) hours, while a DPO representative noted they were unable to join clubs and take part in extra-curricular activities at third level due to ISL interpreters only being made available for classes. Participants also spoke of the shortage of therapists in schools and how Special Needs Assistants (SNAs) are not valued – ‘they get short term contracts’.

Barriers to improving capacity for inclusive education practices included class sizes too big to facilitate personalised supports, lack of investment in Universal Design for Learning (UDL), unsustainable funding programmes, as well as a lack of SNAs and mental health supports. Other challenges included a lack of: learning support hours and qualified teachers; access to assistive technology; alternative education options; occupational therapists and psychologists; local school places; and cooperation between education and healthcare providers.

#### Standards of inclusive education practices

Consultation participants said that different standards of inclusive education practices are also a significant problem. For example, participants argued that while some schools have excellent inclusive practices not all mainstream schools are inclusive so ‘sometimes it is better for disabled children to go to special schools’. Some of the young people consulted reported different educational experiences – some positive, some negative. For example, young people noted several positive supports in education, including the HEAR (Higher Education Access Route) and DARE (Disability Access Route to Education) schemes.

Participants with an intellectual disability who have significant support needs described immense challenges in accessing their right to education. Their supporters/family members described the frustration of applying to multiple schools. One participant, for example, described moving schools multiple times due to a lack of support and understanding of their accommodation needs and rights.

Some reasons given for different standards of inclusion included attitudes of principals and the ethos of schools, inaccessible buildings, a lack of obligation for schools to provide special classes, and how resources for inclusive education seem to be more unevenly distributed in secondary schools.

#### Support and training for teachers

Another major challenge raised involved the lack of teachers and a lack of teachers with appropriate support and formal training for inclusive educational practices. As one focus group participant said, ‘when we work towards mainstream, we should look at the training of teachers and teacher education in how they deal with people with disabilities’.

Participants reported that teachers need to be trained properly to be able to cope with the diverse needs in the classroom and their wellbeing needs to be looked after to help them serve disabled children properly. Participants explained that this challenge of untrained teachers is related to teacher retention, lack of mandatory continuing professional development (CPD) and individual educational plans (IEPs), limited compensation for extra training, and a very small amount of SNA-type training done within the regular teacher training curriculum. One participant also highlighted the need for home tuition support and oversight:

‘I work as a home tutor. There is no oversight at all of my work. So, the students with the greatest trauma and the greatest need, who have to jump through hoops to get a tutor in the first place, are subject to education with no accountability.’

#### Special education policy advice, the Student Support Act, and the EPSEN Act review

Some participants mentioned that it is positive to see the ongoing review of the Education for Persons with Special Educational Needs (EPSEN) Act 2004. Participants welcomed the recently published policy advice from the National Council for Special Education (NCSE), ‘An inclusive education for an inclusive society’. However, some participants also spoke of how the EPSEN Act and NCSE policy advice seem aspirational (i.e., hopeful) in the face of limited supports for inclusive education. As one focus group participant said, ‘we hope the national disability strategy (NDS) would be more ambitious than the EPSEN Act to ensure an adequate and inclusive education system for every child taking into account individual needs’. One DPO representative also highlighted that:

‘The EPSEN act might be progressive but there is a need to build trust and confidence with families because they have little confidence with current system are there is little accountability or recourse for families to take legal routes’

There were also calls for revision of the Student Support Act to eliminate discriminatory assessment criteria. It was felt that the criteria for assessing eligibility for support does not reflect the diverse nature of disabilities (e.g., cognitive disabilities) and does not acknowledge the financial independence of disabled individuals (e.g., when being assessed by parents’ income). In addition to this barrier, DPO representatives also highlighted that Article 24 of the UNCRPD, which governs the right of people with disabilities to receive an accessible and inclusive education in their local community, has never been fully implemented, and only parts of the EPSEN Act have been implemented.

#### Access to education settings

Participants raised challenges related to general access to education settings. As well as problems with inaccessible buildings (e.g., lack of lifts, ramps), they also raised geographic and transport issues with schools, saying, for example, ‘Children have to leave their own community to attend a special school’, and ‘People are travelling hours for a primary education; people need access to their local schools’.

### Pathways and transitions within and between education, training, and employment settings

Consultation participants stressed the challenges and barriers that disabled people face transitioning within and between educational, training and employment settings. They reported difficulties trying to get services and accommodations all the way through primary and secondary school. In one focus group, for example, the participants agreed that the supports must start with the child and then go the whole way through. A DPO representative highlighted:

‘There needs to be gradual transitions for people to feel supported. When people feel included in school, this spreads throughout the rest of society. Supports need to move through transitions with you, and there should be a greater effort to make sure people are aware of supports.’

Another DPO representative brought up the issues with children transitioning into adult services and that support for this is lacking. They pointed to the need to have transition and communication between education, welfare, and health, that services need to be joined-up and that DPOs need to be involved. Transition from school into employment, training or further education was also reported as a major challenge, as one participant reported:

‘Transition [from education] is a huge area that is not discussed. There are loads of transitions that happen at age 18. No support and no pathway. Especially for those with severe/ profound intellectual disability & complex medical needs.’

A further challenge reported by participants with intellectual disabilities was that young people are dropping out of post-primary school due to lack of support which is leading to mental health challenges. They said adult education is not an option for most people with intellectual disabilities.

Across the consultation, participants reported the following challenges that need to be addressed to improve pathways and transitions within and from education settings.

#### Low expectations and discriminatory attitudes

The need for parents and educators to address the challenge of low ambitions and expectations for young students with disabilities was raised. For example, participants explained how low rates of disabled people in higher education and employment are linked to a general lack of expectations of disabled students in school years. Linked to this, participants called for more disability awareness in school settings to change attitudes about disability from an early age. One participant said, ‘if people would be educated from a younger age about the obstacles disabled people face there would be a willingness to gain more knowledge in this area’.

#### Work experience opportunities and career guidance

Participants said all disabled students should have access to work experience as they currently do not. If students do not get those places early to see how workplaces work, they can’t explore different options to help decide what they like and what they are good at. Some participants highlighted how Transition Year is really important for work experience, but it can be hard to get employers to take a transition year student with a disability. These disabled students are often placed in disability organisations that can support them and do not get to experience mainstream working environments.

The issue of the lack of career guidance provided to disabled pupils, in particular in special schools, was also raised. Participants questioned if career guidance counsellors in mainstream schools knew anything about the supports available for young people with disabilities to access work, training, or further education. It was highlighted how this gap is being filled by disability advocacy organisations. One DPO representative recommended:

‘Every pupil needs access to guidance counsellors. We need to make all post school pathways more inclusive. There should be work experience options at school. We need to make sure that disabled people can contribute, and all their needs are met.’

#### Continuity of accommodations

Consultation participants highlighted a problem with a lack of continuity of reasonable accommodations (e.g., assistive technology) for students with disabilities when they move from primary to post-primary or from school to employment settings. For example, a DPO representative stressed that reasonable accommodations should travel with you as the process of disclosure can be draining. They highlighted that having continuous accommodations is really important and must include in-person support. Also highlighted was the challenge of getting reasonable accommodations for those sitting exams and how it was a ‘constant fight’. A DPO representative noted that there can be an incorrect perception that students with disabilities are advantaged by having reasonable accommodations for their education, including during exams.

### Education and training for different disability groups/experiences

#### Disabled women

Participants highlighted a need for inclusive sex education to address a particular challenge for women with disabilities. They said the lack of appropriate sex education contributes to beliefs among the public that disabled people are not fully capable of having relationships or having children.

#### LGBTQI+

LGBTQI+ participants also highlighted a need for inclusive sex education. One DPO representative mentioned how ‘sex education in schools still predominantly focuses on heterosexual and non-disabled experiences’.

#### Travellers with disabilities

Traveller focus group participants reported that Traveller children with disabilities are more likely than others to be on reduced timetables and that SNAs were not always available to Traveller children. Participants linked these experiences to discriminatory attitudes in the education system. A related Traveller-specific challenge involved issues around autism and discrimination, as one quote explained:

‘The volume of children in the Traveller community with autistic spectrum disorder (ASD) is increasing. Parents are taking out loans to get private diagnosis because the waiting list for diagnosis is long, and then sometimes schools are not accessing these private reports. On other occasions, schools are telling parents that their child has autism without a full and proper assessment being undertaken. The result is that children are not fully benefiting from the educational system because the schools they are in are not providing the resources necessary to adequately support the child resulting in the child being placed on reduced hours.’

#### People who are neurodivergent

Participants spoke about challenges facing people who are neurodivergent in educational settings. As one survey responded said, ‘the overwhelming majority of people I know whose children are neurodivergent have had a negative school experience’. Barriers described by participants included rigid approaches to education, a lack of additional time to complete exams, and a lack of training for teachers to understand neurodivergence in education settings. One written submission argued that applied behavioural analysis (ABA) contravenes autistic people’s human rights but is still in use in some schools in Ireland.

Several consultation participants and a DPO written submission highlighted particular challenges for people with dyslexia and dyscalculia, such as: the National Educational Psychological Service (NEPS) does not provide dyslexia or dyscalculia assessments that meet the level of demand from parents or schools; there is a lack of clear policy and practice in schools regarding the amount and type of support a dyslexic or dyscalculic child should receive; and that the full use of assistive technology in schools is not being realised, largely as a result of exclusionary eligibility criteria for the use of technology in State exams.

#### Foetal Alcohol Spectrum Disorder (FASD)

One participant highlighted that Ireland has a high prevalence of FASD but that this is not recognised as disability. They argued that Ireland has the second highest FASD prevalence in the world but 75% of children with FASD leave the education system because they are being excluded, or suspended due to behavioural issues. They said, for example, there are no statutory guidelines for diagnosis and there is a lack of support for children with this condition that can negatively affect education experiences.

#### Migrants and asylum seekers with disabilities

Challenges experienced by disabled migrants and asylum seekers included long waiting times to get initial assessments to access appropriate education systems or supports, a lack of accessible employment options for migrants with disabilities with lower education levels, educational qualifications from home countries being considered lesser, delays in getting children with disabilities into schools, and transport barriers for parents in getting their disabled children to their schools.

#### Deaf people

d/Deaf participants and Deaf DPO representatives stressed that inclusion is not one size fits all for d/Deaf young people. They reported pros and cons of mainstreaming and Deaf schools for different individuals, but the system encourages universal approaches. The lack of Irish Sign Language (ISL) interpreters and ISL teachers was the major reported barrier to education and training for Deaf people. Barriers to training include experiences such as training courses requiring two Deaf people to enrol before ISL is provided. There are also reported difficulties sourcing high quality ISL interpreters in education systems.

Deaf DPO representatives explained a significant problem is that the Government listen more to the hearing professionals that work with Deaf people rather than Deaf professionals from the Deaf community. They said that in the ISL Act it is not currently mandatory that teachers should have ISL fluency. Therefore, young Deaf people experience language deprivation syndrome as they are not getting access to teachers with ISL fluency. Some d/Deaf children who are forced to learn English have no first language fluency. Research shows that d/Deaf young people who went to mainstream schools can struggle with their emotions in later life because they did not get to experience education with their language preference (i.e., ISL). One DPO representative explained the culture shock they experienced when they transitioned from a Deaf school to mainstream university, such as how it is assumed that Deaf people know English. ISL, DPOs highlighted, is not only for d/Deaf children (e.g., it can also be a way of communication for some non-speaking children).

### Irish language reform

One submission focused on how: ‘in Ireland, one of the biggest cases of discrimination on the basis of language is the Irish language exemption system’. They highlighted that instead of accommodating the special educational needs (SEN) of students with disabilities, they are given an exemption from the study of Irish. This means that disabled students can be limited in career opportunities later in life. This submission argued:

‘The Irish language in the education system needs to be fundamentally reformed to ensure that it is accessible to every school student in the country.

## 5.7.2 Proposed actions and solutions

Consultation participants proposed many actions and solutions to address challenges regarding education and training in the new National Disability Strategy. The recommendations include general approaches required to improve education for disabled people as well as specific actions around building capacity and supporting transitions through and out of education settings.

### General approaches and principles to improve education for disabled people

* Be more ambitious than the EPSEN Act to ensure an adequate and inclusive education system for every child that considers individual needs (DPO contribution);
* Set out a roadmap for what inclusion looks like in practice (DPO contribution);
* Consider the increasing inclusiveness of education as an ongoing process (the NDS needs to put the wheels in motion towards gradual transformation) (DPO contribution);
* Define what an inclusive learning environment looks like (DPO contribution);
* Use a child-centred rights-based inclusive educational model (DPO contribution);
* Take a Universal Design for Learning approach to education (flexible and adaptable approaches) (DPO contribution);
* Consider the present and future educational needs of disabled people (DPO contribution);
* Consider the psychological impact and feeling of belonging of being a student in a non-inclusive educational environment (DPO contribution);
* Look at how language around disability could be changed to promote cultures of inclusive education (e.g., ‘additional/special needs’) (DPO contribution);
* Put the ethos of the UNCRPD into the strategy so that the educational environment adapts to people’s needs rather than adapt people to fit the environment (DPO contribution);
* Consider early interventions in education settings for children aged 0-6 as vital (DPO contribution);
* Consider the suitability of behavioural interventions in educational settings (e.g., Applied Behaviour Analysis) that are underpinned by ableist notions (DPO contribution); and
* Ensure school communities and educational stakeholders at the core of our educational system promote inclusive school cultures.

### Actions to build the capacity of systems for inclusive education practices

#### Actions to improve supports and resources

* Provide more funding to schools for SNAs and autism classes, to ensure every child in every school gets the support they need;
* Encourage or incentivise private education service providers to invest more in educational opportunities for people with disabilities;
* Introduce personalised budgets that allow people to fund their own education;
* Require inclusivity plans in schools;
* Allow parents/guardians of children with complex needs to secure school places a year earlier than others;
* Set up a system where supports and resources are automatically in place as disabled children are coming into education systems;
* Have an adequate number of school places locally for children with complex needs;
* Improve signposting to education supports, particularly for seldom-heard-from groups and those who face communication barriers;
* Resource Delivering Equality of Opportunity in Schools (DEIS) schools to appropriately support children with additional needs;
* Ensure more flexibility to ensure PA hours will be available to adapt to changing third level educational schedules;
* Allocate a specific person responsible for disability in every school to, for example, support SNAs and manage situations where children with disabilities are being bullied;
* Place more therapists in schools and colleges, so all children and young people can get help with communication, handwriting, concentrating, and technology;
* Fund high-quality interactive whiteboards in schools that are accessible to all children and young people;
* Ensure access to appropriate schoolbooks for children with vision impairment;
* Provide camps to support children with specific disabilities to learn life skills, for example, cooking, using public transport;
* Provide courses to teach children and young people how to manage money and use a bank;
* Ensure access to appropriate school transport systems (DPO contribution);
* Include statutory guidelines that regulate practices like Codes of Behaviour, seclusion and restraint, reduced timetables;
* Integrate individualised supports into education settings such as Special Needs Assistants (DPO contribution); and
* Have Teaching Assistants/SNAs in each classroom for at least half the day.

#### Action to address standards of inclusive education practices

* Highlight and share examples of good inclusive education practice through the lifetime of the strategy.

#### Actions relating to support and training for teachers and SNAs

* Provide more teacher training and upskilling for teachers and SNAs in supporting children with disabilities, including neurodiversity;
* Compensate teachers who are working with students with additional educational needs (AEN) for extra training; and
* Make sure that every SNA is willing and able to give basic medications such as to inject insulin/administer emergency medication for epilepsy.

#### Actions to improve existing inclusive education policies and legislation

* Review the EPSEN Act and engage in more cross-sectoral working in line with the ‘Young Ireland: The National Policy Framework for Children and Young People 2023-2028’ policy;
* Include Disability Equality Training in the EPSEN Act;
* Fully enact/implement the EPSEN Act to ensure that children/students are getting educational plans that suit their needs early in the year;
* Develop a ten-year implementation plan, and design a communications plan, to make NCSE policy advice a reality;
* Ensure that NCSE policy advice is UNCRPD compliant (it was noted General Comment No.4 on UNCRPD Article 24 is very helpful in outlining the steps needed);
* Statutorily recognise Individualised Education Plans (DPO contribution);
* Continue investment in initiatives like AIM that enable children with disabilities to access pre-school education;
* Recognise that the National Charter for Universal Design in third level education could be of benefit to other education sectors;
* Amend discriminatory sections of the Student Support Act so that all disabled students are classified as independent for funding purposes; and
* Expand SUSI grant eligibility so that people with disabilities qualify on this condition alone irrespective of household income.

### Actions to address transitions within and between education and employment settings

#### Career guidance

* Ensure every student (disabled or non-disabled) in special or mainstream settings receives career guidance;
* Deliver tailored career guidance as early as possible for people with disabilities with a long-term plan from school to graduate to employment;
* Deliver Disability Equality Training to career guidance counsellors; and
* Address the systemic lack of ambition and limited access to post-primary education and career guidance for students in special education schools.

#### Continuity of accommodations

* Introduce an accommodations/assistive technology passport that travels with people with disabilities throughout their education journey;
* Clearly outline a continuum of support through primary school into secondary school. Consider reasonable accommodations needed in school and required to get to school (DPO contribution); and
* Develop a portal to access supports, particularly through transitions (DPO contribution).

#### Disability awareness and equality in schools

* Increase disability awareness in schools by integrating disability equality/awareness into educational curricula, including Transition Year;
* Support DPOs to deliver Disability Equality Training in schools (DPO contribution); and
* Deliver anti-bullying initiatives in school and provide more support for schools when bullying occurs due to disability or neurodivergence.

#### Other actions to address transitions and pathways

* Collect data on disabled children’s outcomes after leaving school. This should be part of how the NCSE evaluate progress in inclusive education;
* Develop a one-stop shop for applications to further education;
* Address the shortage of support staff for students in third level education;
* Provide more support to graduates with disabilities leaving college;
* Set up a job placement service with ongoing monitoring and support to bridge the gaps in the transition and settling into employment;
* Address the lack of applications from people with disabilities in apprenticeships. Create more awareness of and supports in apprenticeships; and
* Introduce initiatives/events to help those with a disability to gain important skills, like literacy, social and leadership skills, etc.

### Actions to address unique barriers for groups with different disability experiences.

#### Actions for disabled women and LGBTQI+ people

* Deliver inclusive sex education in schools that centres lived experience and includes discussions around consent and ways of making intimacy and sex accessible to all.

#### Actions for Travellers with disabilities

* Include a specific focus on the education of Traveller children/young adults with additional needs in the National Disability Strategy;
* Provide more supports in early education for Traveller children with a disability; and
* Deliver anti-racist training to teachers.

#### Actions for people with intellectual disabilities

* Provide more courses to support people with intellectual disabilities to buy and learn to use assistive technology;
* Provide courses for people with intellectual disabilities to support them to manage and be in control of their own money;
* Allow people with intellectual disabilities to study at their own pace and with fewer deadlines;
* Focus on raising awareness within the education sector about post-secondary options for individuals with intellectual disabilities; and
* Address the cost of upskilling, to think more broadly about people’s ‘talents’, and have more tailored options for school leavers with intellectual disabilities.

#### Actions for neurodivergent people

* Create more places for autistic and neurodiverse children in mainstream schools;
* Encourage the introduction of quiet rooms and sensory spaces in colleges and universities so people with autism can have a break;
* Amend the Reasonable Accommodations at Certificate Examinations (RACE) scheme to be more like the Disability Access Route to Education (DARE) application that leaves room for interpretation of the impact of disability on the young person;
* One written submission from a DPO contributed a detailed plan to reform education and training for people with dyslexia and dyscalculia including:

1. all individuals should have access to professional assessment for dyslexia and dyscalculia, irrespective of their ability to pay privately,
2. better access to key supports and accommodations for dyslexic and dyscalculic individuals,
3. NEPS need to increase the number of assessments for dyslexia and dyscalculia for school-aged children and young people,
4. there needs to be publicly funded assessment opportunities for adults who were missed while in school.

#### Action for Foetal Alcohol Spectrum Disorder (FASD)

* Recognise with urgency the challenges relating to FASD in education and change ‘Code of Behaviour’ guidelines in schools to ‘Code of Conduct’ guidelines to accommodate for FASD behaviours.

#### Action for migrants or asylum seekers with disabilities

* Provide earlier initial disability assessment to asylum seekers to facilitate access to appropriate education systems.

#### Actions for d/Deaf people

* Provide early intervention support with an emphasis on language acquisition and access to ISL;
* Ensure every Deaf child has a fully qualified ISL special assistant teacher; Consider enforcing legislation to this effect;
* Teach Irish Sign Language in schools, in the Leaving Certificate curriculum and at third level;
* Aim for increases in applications to DARE and the numbers of d/Deaf students graduating from third level education;
* Provide training and awareness programs for educators on Deaf culture and effective teaching methods for d/Deaf learners;
* Place a specific focus on improving teacher CPD in teaching Deaf students and minimum levels of ISL competency for teachers;
* Enact inclusive education policies that ensure d/Deaf students have access to quality education with appropriate accommodations and support;
* Put in place, and enforce policies, to teach ISL at a high standard, in a similar way to how Irish language schools teach Irish language at a high standard (DPO contribution); and
* Collate data on educational outcomes for d/Deaf children in the primary and secondary system.

### Irish language reform

* Develop an integrated and coherent policy for the Irish language in the education system from early childhood education to third level based on inclusive education that caters for the needs of students with disabilities, and does not encourage nor facilitate exclusion; and
* Have the National Council for Special Education (NCSE) develop a training course in the Irish language aimed at special educational needs assistants in Irish-medium and Gaeltacht schools.

# 5.8 Employment

## 5.8.1 Context and challenges

Throughout the consultation, participants called for better employment opportunities for disabled people. Participants referenced the particularly large disability employment gap in Ireland and expressed frustration at the lack of progress in closing the gap over recent years. A number of participants raised questions, concerns, frustrations, or disappointment over the stalled implementation of the Comprehensive Employment Strategy for People with Disabilities.

Participants spoke of the large proportion of disabled people who want to work, and advocated strongly that it should be made easier for them to do so. Several discussed the importance of employment for disabled people’s well-being and inclusion, mentioning both economic and social benefits. For example, a disabled young person stated: ‘I want to earn enough money so I can care for my parents when they are older’. The high rate of being at risk of poverty and social exclusion among disabled people in Ireland was raised in the context of employment.

The value that disabled people bring to workplaces was highlighted by many participants. However, it was emphasised by DPOs and others that not all disabled people are able or feel able to work and that they should not be pressured to do so. Examples were given of people who did not want to risk working for fear that it would accelerate the progression of a condition or illness or interfere with treatment schedules. It was expressed that disabled people should be able to have a decent standard of living whether they are in a position to work or not and that an individual’s worth should not be tied to their economic value.

Consultation participants described many barriers to employment for disabled people in Ireland. It was emphasised repeatedly that while there are common employment barriers facing disabled people in Ireland, there are also challenges specific to different groups that should be addressed in the next National Disability Strategy. There are barriers to employment reported by autistic people, for example, that differ from those facing people with physical disabilities or mental health difficulties. According to participants, there are also different employment barriers facing people who were born with a disability, people who acquired a disability early in life, people who acquire a disability in the course of their working life (for example, as a result of illness, injury, or ageing), and people who receive a diagnosis (e.g., of autism, ADHD, or mental health difficulties) while working. Different policy actions have been suggested to meet the needs of these different groups, as well as recommendations for addressing barriers common to all disabled people.

Several participants advocated for the inclusion of employment targets for people with disabilities in the National Disability Strategy. It was recommended that the new strategy clearly state an aim for how many more disabled people will enter employment over the lifetime of the strategy. It was advised that any targets and measures should be realistic, and that the strategy should clearly set out: ‘This is where we are, and this is where we want to be’ when it comes to the employment of people with disabilities in Ireland.

Several participants also spoke favourably of employment quota schemes in other countries, and DPOs and others called for private sector quotas, positive discrimination and/or affirmative action policies to be introduced, or at least considered, in Ireland. However, a small number of consultation participants raised concerns about the efficacy of quotas, including that quotas can lead to tokenism and that they do not address the issue of underemployment among disabled people.

### Employer-side barriers

#### Inaccessible recruitment processes

Consultation participants reported that recruitment processes are often inaccessible and tend not to be ‘disability proofed’. It was argued that disabled people are unlikely to apply for roles if there are phases of the recruitment process that are inaccessible. The language of job advertisements was raised repeatedly. The prevalence of language like ‘fast-paced environment’ was reported as ableist. The condition that candidates must have a full, clean driving licence was also raised as a barrier for some disabled people. For example, in a written submission, one individual wrote:

‘One of the main barriers is that most of the job specifications say that applicants must have full, clean drivers' licenses and access to transport. I use a handcycle and between walking or using my handcycle, public transit and occasional taxis, I am well able to get wherever I need to go without issues. But as soon as I mention on the application that I do not have a car or license, I feel that is an immediate route to disqualification. But it shouldn't be because all the jobs I have applied for with those requirements are those that could be accommodated in some way (desk work where driving is only a tiny part of the job and not part of the daily duties, etc.)’

It was also raised that recruitment processes are often inaccessible to neurodivergent people. One DPO indicated that autistic people often have the skills and qualifications for a role but have difficulty with standard phases of recruitment processes such as producing cover letters/CVs and interviewing.

Disabled participants spoke about the barriers they had personally encountered when seeking employment. For example, after being offered a job interview, a recruitment process stalled when the candidate requested an ISL interpreter. Another participant explained that the amount of red tape involved in order to pay for an ISL interpreter through the Job Interview Grant deters many Deaf people from applying for jobs.

In another instance, a person with mobility issues described being called to interview, being asked if their mobility issues were permanent, and then being immediately ruled out of contention for the role. Other people with physical disabilities feared that they would be disqualified if they attended for interview and the workplace was inaccessible, as they were concerned that the employer would simply find it ‘easier’ to hire another candidate.

#### Lack of reasonable accommodations

It was reported repeatedly that there are fears among many employers about what is involved in hiring a disabled person, that there is little awareness of funding available for reasonable accommodations, and that employing disabled people is often wrongly perceived as ‘too costly’. Participants said that applying to the Reasonable Accommodations Fund is bureaucratic and burdensome and the uptake of the scheme very low.

It was also reported that employers often construe ‘reasonable accommodations’ very narrowly, perceiving it to only apply in the case of some disability types or believing that it only refers to costly workplace adaptations, equipment, or ISL interpreters. For example, it was reported that some employers did not believe that reasonable accommodations applied in the case of mental health difficulties. Participants discussed that a majority of reasonable accommodations have little to no cost and instead relate to ‘ways of working’. However, consultation participants spoke frequently about a common lack of flexibility around working arrangements on the part of employers that disproportionately disadvantages disabled people and those with chronic illnesses.

One DPO representative spoke about how lack of flexibility on the part of employers about ways of working presents barriers for autistic people. Issues include rigidity around normal working hours and the ability to work from home. Other participants raised issues such as difficulties taking time off work to attend medical appointments, needing flexibility when adjusting to new medications, and difficulties wearing uniforms due to sensory issues.

Overall, there was a strong sense that it should be easier to get reasonable accommodations from employers and that, if this were the case, employment levels among disabled people would be considerably higher. When asked what they wanted to see change as a result of the new strategy, one survey respondent wrote: ‘Not having to prove you’re very disabled to get accommodations.’

#### Awareness, attitudes, and discrimination

Discriminatory attitudes and lack of disability awareness among employers was experienced as an ongoing issue by some consultation participants, who reported a common assumption that disabled people lack education or skills or that they would be ‘unreliable’ employees. Discrimination was reported in hiring practices as well as in workplaces. Consultation participants spoke of ‘stereotypes’, ‘misconceptions’ and ‘lack of understanding’ among employers in relation to disability.

It was reported that fear of discrimination can prevent people from disclosing a disability to an employer, either during the recruitment process or while in employment, meaning people cannot access accommodations that would help them to succeed in obtaining, maintaining, or progressing in employment. It was felt that many employers simply did not understand disability. It was also expressed that some employers do not understand the value that disabled people can bring to employment, and see their employment as a ‘charitable’ or tokenistic act. Comments from children and young people on this theme included: ‘There is a sense that there’s a neurotypical person ready to come along and take the job…so why would an employer want you?’

It was also reported that there is a lack of awareness, understanding and competence among employers around how to best support people returning to work after they have acquired a disability. Support needs can be highly individual and should be dealt with appropriately on a case-by-case basis, but this is not well understood. Engagement around planning for return to work is often left too late, according to consultation participants (see section on vocational rehabilitation below).

Consultation participants also expressed that there are intersectional issues (i.e., unique barriers faced by disabled people who come from other marginalised groups) to be considered. For example, as there are low employment rates among Travellers and among disabled people, disabled Travellers face more barriers to accessing employment. These include discrimination and a lack of cultural awareness among some employers.

### Educational barriers

It was mentioned by some participants that disabled people have lower educational attainment, on average, than people without disabilities and that disabled people may not have the qualifications or relevant skills for employment in sectors in which they have interest. Issues such as low literacy and ICT skills among some disabled people were raised as barriers to work. One participant cited research showing that graduates with disabilities are disproportionately graduating from the ‘lowest-outcome’ (e.g., in terms of income or employability) degree courses. Upskilling and training were identified as an important part of the picture of disability employment. Again, linking to intersectionality, it was raised that there can be particular qualification barriers for disabled migrants, whose qualifications from their countries of origin may not be recognised or valued as highly in Ireland.

Other consultation participants spoke about how for people with intellectual disabilities, lack of employment opportunities can be linked with discrimination faced in the education system. Low expectations of people with disabilities and lack of appropriate career guidance on employment routes and employment supports for disabled people are major issues, according to one DPO representative. There were calls for clearer pathways for disabled people to progress through education and into employment, particularly for people with intellectual disabilities. Several participants reported that career guidance and work experience opportunities tend to be very limited in special schools and that it is very important that the strategy recognise the link between employment and education and training. The importance of structured opportunities for work experience and volunteering was also raised by children and young people who participated in the consultation.

It was reported as difficult for further education and training (FET) providers to establish links into employment for people with intellectual disabilities (e.g., for work experience placements) and that where organisations do have good employment programmes, these were Dublin-centric. Courses for people with intellectual disabilities were also perceived to be centred in Dublin. Some participants mentioned being aware of the Trinity Centre for People with Intellectual Disabilities and felt that there should be similar centres around the country.

### Issues with social welfare services and schemes

#### Disability payments

It was repeatedly reported by consultation participants that there is a real fear among disabled people of leaving behind disability payments such as disability allowance (DA) and invalidity pension after taking up employment. Despite reforms in this area, it was raised by DPOs and others that if employment does not work out, the route back to receiving disability payments is perceived as incredibly difficult and, for many, not worth the risk. It was also repeatedly raised that the income disregards for disability payments are too low and that this serves as a disincentive for people to take on more employment.

#### Secondary benefits

Potential loss of the medical card after becoming employed was raised, by DPOs and others, as a major prohibiting factor for many disabled people to take up employment. This issue was mentioned in almost every discussion on employment throughout the course of the consultation and was emphasised as one of the primary barriers to employment for people with disabilities in Ireland. In a video submission, one consultation participant said:

‘With the help of my Assistive Technology solutions, I’m grateful to have a job. But I have one main worry. That is that I lose my entitlements. And I’m not only worried about the financial aspect, I’m also worried about losing my travel pass and my medical card.’

Participants also spoke about expensive medications, treatments, and equipment that they simply could not afford without the medical card, even when in employment and earning an income.

#### Wage Subsidy Scheme

Several consultation participants expressed that the Wage Subsidy Scheme (WSS) is crucial for increasing the employment rate of disabled people, but that, it requires reform to do this. Participants referred to the ‘inflexibility’ of the scheme, highlighting, for example: ‘The Wage Subsidy Scheme is urgently in need of reform and restructuring to allow greater flexibility and to help it sustain more employment opportunities.’ One participant explained that their employer could not avail of the WSS because they (the employee) were in receipt of the Invalidity Pension. Another called for the expansion of the scheme to anyone with a chronic illness diagnosis, while another called for a restoration of the link between the scheme and the national minimum wage. One participant argued: ‘Combined system of wage subsidy scheme and universal basic income is required to replace disability allowance.’

A small number of participants, including a DPO representative, expressed objections to the premise of the scheme, namely the deficit framing of disabled people as being ‘less productive’ than others. One participant argued that the funds paid to employers through the scheme would be better allocated directly to disabled people to pay for the supports they need to be successful in employment. Others suggested that the framing of the scheme be changed. For example: ‘replacing the loss of productivity clause with a more positive rationale.’

#### Reasonable Accommodation Fund

The low uptake of the Reasonable Accommodation Fund was raised repeatedly, including by DPOs. One participant cited research indicating that only 26% of employers are aware that the fund exists. Even among those who are aware of it, applying to the Reasonable Accommodation Fund is perceived as onerous. There was also a sense that the fund can be rigid and, consequently, not fit for purpose. An example was given of a disabled person whose employer applied for a new piece of equipment, as the equipment that the person had been using had become obsolete. However, the employer was informed that because they had applied for funding for a similar piece of equipment for this person 17 years prior, that the new equipment would not be funded. It was perceived that there was no understanding among those administering the fund that technologies evolve and that just because an employer receives funding for a piece of equipment at a given point in time, this does not mean that newer or more productive equipment will not be required at some later date.

It was also raised as an issue that where an employee has accessed a piece of assistive technology (AT) through the Reasonable Accommodation Fund and that employee then leaves the employing organisation, the equipment or AT stays with the employer, even though it may no longer be of need or of use there, rather than following the person with the disability. In addition, a very small number of participants spoke about difficulties in accessing the job interview and personal reader grants through the Reasonable Accommodation Fund.

### Employment services

Throughout the consultation, many participants called for improved employment supports for disabled people in Ireland. Some participants advocated for the expansion of services like EmployAbility. While one participant stated that EmployAbility was doing ‘an excellent job’, people generally found the employment supports for disabled people insufficient. Specific criticisms levelled at EmployAbility included long waiting lists, a requirement to be ‘employment-ready’ before engaging with the service, and the service itself not being suitable for diverse disability types. Some participants described unsuccessful engagement with the service, saying for example: ‘I know about [the] EmployAbility programme. I used it myself, but it is far from a successful programme. They were not able to find anything for me at all, not a single interview.’ Another person who felt that they were underemployed did not feel that they could access support to seek more suitable employment:

‘I am aware of the EmployAbility service, but it seems to be for people who are out of work and want to return to it, so I don't think I qualify based on that I am working now and just want a different position.’

Several consultation participants indicated that it was difficult to access job coaches and called for more to be employed.

It was reported by DPOs and others that there is an overemphasis on the medical model and ‘diagnosis’ in employment and social welfare services for disabled people in Ireland. One DPO raised the issue that staff in employment services are often ill-equipped to be inclusive of people with disabilities and that disabled people often experience not being believed in their interactions with staff.

#### Difficulty accessing other services and supports

Consultation participants reported barriers to accessing a range of other services and supports that would help disabled people to obtain and maintain employment. Difficulty accessing personal assistance during the working day was reported as a major employment barrier for some people with disabilities. Despite the Irish Sign Language Act 2017, accessing an ISL interpreter was found to be a ‘huge challenge’, although less of an issue in the public than the private sector as a result of the Act. It was noted by one DPO representative that private sector employers do not provide ISL interpreters, both for attitudinal reasons and lack of awareness, with employers regarding the provision of ISL interpretation ‘as too much hard work’.

It was reported in one focus group that people with intellectual disabilities who do not accept a HSE-funded day service place by the age of 22 will lose eligibility for that service. Fear of not being able to access a service later was reported to deter people from pursuing further education, training, or employment.

Several participants raised the issue of insufficient supports available to self-employed disabled people/disabled entrepreneurs. Reported barriers to self-employment among disabled people include a lack of awareness of the viability of such a path. In a written submission, one respondent wrote:

‘There is a distinct lack of awareness or promotion of self-employment as a viable option to labour market participation for people with disabilities. People with disabilities are not visible in the promotional materials produced by enterprise agencies, nor are their needs addressed in a customised manner.’

This submission went on to outline further barriers, including that the ecosystem of supports for entrepreneurs is not tailored to people with disabilities and that there is no signposting of information relevant to disabled people aspiring to self-employment. The importance of supporting entrepreneurship was also raised in a focus group with disabled children and young people, with one young person stating:

‘Entrepreneur is a good path for a lot of Autistic people because we all have our own special interests and it’s hard to get a job especially if you don’t have higher education. I make a lot of my own things so I can see that in my future.’

It was raised by DPOs and others that a lack of appropriate public transport services, including issues with the accessibility of trains and buses and the availability of taxis, remains a significant barrier to employment for many people with physical and other disabilities. Lack of availability of accessible transport was reported as causing issues for disabled people already in employment, for example leading to punctuality issues. It was also highlighted that public transport can be unsafe for some disabled people, including people with physical disabilities and people with chronic illnesses and compromised immune systems who risk infection when travelling in this way. In such cases, travelling to a job can be particularly problematic and/or expensive.

In a focus group with migrants with disabilities, some participants were waiting for work permits before seeking work. Despite wanting to work, concern was expressed about how they would make employment work without accessible childcare.

#### Lack of Vocational Rehabilitation

Some consultation participants discussed barriers to people returning to sustainable employment after leaving the workplace as a result of the onset of a disability or long-term illness. It was reported that there is a very low rate of uptake of the Employee Retention Grant and low awareness among employers of its existence. A small number of participants explicitly called for a national policy and system for vocational rehabilitation in Ireland, stating that Ireland lags behind other countries in this regard.

Participants spoke too about how the supports needed to facilitate a successful return to work for an individual who has acquired a disability are often not well understood or are difficult to access. They said, for example: ‘those who acquire a disability during their working life often find that when they return to work, they don’t receive wrap around supports, for example, PA and transport supports.’

It was further argued that there is a need for training for employers and employees to better understand how a person who has acquired a disability can best be supported in work. An example was given of an individual who had acquired a disability and, instead of the employee and their employer working together or receiving training to determine how he/she could be supported to return to work, the employee was told that their only option was to work from home.

#### Lack of opportunities

Repeatedly raised throughout the consultation was the lack of appropriate employment-related opportunities for disabled people in Ireland. It was advised that disabled people do not just want ‘any job’, but quality employment. Some disabled participants spoke about being unable to obtain anything other than low-paid or unpaid employment. Disabled participants also spoke about feeling unable to follow their interests or to develop career paths that are meaningful and fulfilling to them, because barriers to employment are greater in some sectors than in others.

Small numbers of participants called for more opportunities to volunteer or for greater employment opportunities for disabled people to ‘work in the disability sector as advocates and supporters.’

Underemployment was also raised repeatedly as an issue, including by DPOs, with how disabled people report fewer promotion opportunities than peers without disabilities. This issue was raised, for example, as a prevalent issue in the Deaf community by one DPO representative, who reported that many Deaf people stay in the same roles for a long time due to a lack of promotional opportunities. It was reported that there is a perception among employers that it is too complicated to provide the necessary training and supports for Deaf people to take on senior roles due to the need for interpreters, etc. Participants spoke about the high numbers of Deaf people emigrating to the UK, where there are better employment opportunities and in-employment supports for Deaf people.

Expectations about the types of employment that disabled people can undertake were reported as particularly constraining for some groups, such as people with intellectual disabilities.

## 5.8.2 Proposed actions and solutions

Consultation participants offered many suggestions for addressing employment barriers for people with disabilities in the new National Disability Strategy. These include actions targeting employers, social welfare services, employment supports, education and training, and quotas and targets.

### Employer-focused

* Provide greater education and awareness raising among employers around employing disabled people, on reasonable accommodations, and on the value that disabled people can bring to employment. Disabled people may be the best educators (contribution from DPOs and others);
* Provide clarity on what represents ‘reasonable’ accommodation and ensure greater accountability on the part of employers for delivering said accommodations (DPO contribution);
* Compel employers to provide reasonable accommodations and hold them accountable if they fail to do so. Levy greater penalties for employers who are found to have discriminated against disabled employees or job candidates;
* Raise awareness of employees, so that disabled people are aware of accommodations they can seek;
* Incentivise employers (including financially, e.g., through tax incentives) to employ disabled people/people with chronic illnesses and promote disability awareness among employers to allay fears. Actively address the very low uptake of several existing supports for employers;
* Provide guidance and support to employers to ensure that recruitment processes are accessible, starting from the language used in job advertisements through to candidate screening and selection processes. Applications from disabled people should be explicitly encouraged and ableist language removed;
* Encourage employers to show greater flexibility in terms of working arrangements if employment rates among disabled people are to increase, particularly in terms of working hours and remote working (contribution from DPOs and others).
* Foster better links between disability employment services and employers. Linking with equality, diversity, and inclusion (EDI) groups in employers is one way for employment services to do this; and
* Conduct a study to capture ‘baseline’ data on attitudes among employers in relation to hiring people with disabilities. Any change in attitudes can then be tracked over time.

### Social welfare services

* Expand the Wage Subsidy Scheme and make it more flexible;
* Expand and reform the Reasonable Accommodations Fund, including by making public sector organisations eligible for funding, being flexible in terms of what can be funded, and raising awareness of the fund among employers (contribution from DPOs and others);
* Increase income disregards for disability payments (contribution from DPOs and others);
* Conduct a cost-benefit analysis on the possibility of retaining secondary benefits when moving off disability allowance payments;
* Allow permanent retention of secondary benefits such as the medical card and free travel for disabled people who take up paid work, which will remove a significant barrier to employment (contribution from DPOs and others);
* Ensure that it is straightforward and quick for someone to return to a disability payment if employment does not work out;
* Expand and reform EmployAbility, including by hiring more job coaches, providing more training for staff, and ensuring the service is fit for use by people with diverse disability types;
* Ensure all Intreo staff receive disability equality training aligned with the social model of disability (contribution from DPOs and others);
* Ensure staff offering employment supports to Travellers with disabilities receive appropriate cultural awareness training to understand the specific supports a Traveller may need to enter and sustain employment;
* Increase awareness of the Employee Retention Grant; and
* Introduce a national policy and system for vocational rehabilitation.

### Education, training, and career guidance

* Improve access to higher education, further education and training (FET), and other training and ensure the link between education and employment recognised in the strategy (contribution by DPOs and others);
* Ensure more reasonable accommodations and better routes to employment for disabled people in higher education and FET, particularly for people with intellectual disabilities;
* Provide more and better career guidance and work experience programmes for disabled young people in Ireland, including in special schools;
* Deliver support for disabled people to upskill and/or retrain, where necessary, in order to obtain high-quality employment and progress in their careers; and
* Introduce specific internship and apprenticeship schemes for Travellers with disabilities.

### Accessing employment and employment supports

* Fund community organisations to ensure they have the capacity to take on and support disabled volunteers, as many of the skills that people need for accessing paid work can be learned from voluntary work. It is important to make sure that volunteering translates to opportunities for paid work, if that is an individual’s goal;
* Support disabled people, as people with lived experience of disability, to work in the disability sector as advocates and supporters;
* Provide access to employment or career supports as part of the remit of community mental health teams;
* Capitalise on the new opportunities that remote working provides for people with disabilities but ensure that disabled people have the choice of whether they wish to work remotely. Ensure the increasing normalisation of remote work does not let employers ‘off the hook’ for ensuring that workplace premises are accessible (contribution from DPOs and others);
* Provide better support to ensure that self-employment is a viable route for disabled people, including through awareness raising and the provision of adequate information and supports on this alternative to labour market participation (contribution from DPOs and others);
* Ensure a coordinated, collaborative, cross-government approach to increasing employment opportunities for disabled people;
* Ensure that supports such as personal assistance and ISL interpretation are readily available to disabled employees (contribution from DPOs and others); and
* Introduce a programme in Ireland programme that is similar to the UKs Access to Work scheme (DPO contribution).[[19]](#footnote-20)

### Targets and quotas

* Include explicit targets for increasing the employment rate of disabled people in the strategy. These should be specific, measurable, time-bound, ambitious, and realistic, e.g., an increase to the EU average disability employment rate within the lifetime of the strategy;
* Consider introducing targets for specific groups, such as an increase in the employment rate of people with intellectual disabilities above 30%, a 10% increase in the number of disabled people (particularly women) who are self-employed, or that 50% of employers receive disability equality or awareness training in the lifetime of the strategy;
* Review the minimum public sector target for disabled people. Consider increasing the target, e.g., to 10% (DPO contribution) and extending it to NGOs and the private sector;
* Ensure better monitoring and auditing of the public sector target.
* Consider introducing employment quotas or other positive discrimination measures for disabled people in Ireland, including in the private sector (contribution from DPOs and others); and
* Make use of procurement processes to advance disability employment in Ireland, for example through procurement quotas for social enterprises or other providers who meet disability employment thresholds.

# 5.9 Financial independence and security

## 5.9.1 Context and challenges

A strong message from consultation participants was the importance of financial independence and security for people with disabilities – through employment for those who can work and from the social protection system.

Throughout the consultation, many participants referred to the financial challenges of living with a disability or caring for someone with a disability in Ireland, and the extra costs incurred when living with a disability (please see Chapter 6 for consultation feedback on the financial challenges of caring for someone with a disability). Consultation participants reported ways in which the current system of benefits and entitlements does not facilitate an adequate standard of living for people with disabilities or their families in Ireland. Many consultation participants reported that the current levels of allowances and benefits do not enable them to live full lives, and that families are ultimately penalised in the current social protection system if they have a family member with a disability. Financial issues are compounded when families have more than one disabled family member. A DPO representative and other participants referred to the invisible, indirect costs of not having the means for an adequate standard of living, including frustration, pain, stress, burnout, psychosocial disabilities, mental health issues, social isolation, and trauma. There was a sense from the consultation feedback that people felt trapped in their current economic situation.

Wider systemic issues impacting on disabled people’s financial independence and security, including access to and progression in education and employment, as well as the current cost of living crisis, were mentioned as compounding the financial challenges faced by people with disabilities in Ireland. Issues with public services and supports (e.g., health and transport) were frequently raised as being responsible for significant extra costs of living for those with a disability.

### How the economic situation of disabled people is viewed

Consultation participants urged the government to change the lens through which they consider the economic situation of disabled people. Several DPOs felt the economic situation of disabled people needs to be considered through UNCRPD/human rights/social model/holistic lenses. A number of DPO representatives also recommended that issues of social welfare and the cost of disability be considered separately – that there is a problematic conflation of income and compensating for the cost of disability. Another participant noted: ‘The government has to stop seeing disabled people as a cost and how to manage a cost, they have to start seeing value in participation.’

### Extra financial costs of living with a disability

The additional cost of living with a disability in Ireland was mentioned throughout the consultation. Indecon’s 2021 report on The Cost of Disability in Ireland was raised quite often, with participants quoting the range of extra costs faced by people as a direct result of having a disability (e.g., the report estimated an annual additional cost of disability across their survey respondents of €11,734). It was acknowledged that there is not a single ‘cost of disability’, rather costs depend on individual circumstances. There was a sense of frustration expressed by some participants that nothing had changed since the publication of this report, including that government budgets since then have not acknowledged this extra cost of disability. It was also noted that due to the rise in inflation the extra costs of living with a disability will be higher than outlined in the report.

DPO representatives and many other respondents specified numerous areas where they are likely to have to spend more money due to having a disability, including:

* Health, medical, and social care services, supports and therapies – those that are not covered under relevant schemes, for those who do not have a medical card, and for many people who pay for private provision of supports. Consultation participants talked about having to pay privately for therapies and equipment due to long waiting lists, long delays, services not being available, or in a case where the HSE did not have the necessary expertise in their condition. It was noted that the cost of these therapies and equipment are high, and are increasing, with one describing private services as ‘extortionate’;
* Medication – which is not covered or fully covered under relevant schemes, for those who do not have a medical card;
* Transport – when public transport is not available or accessible, for those living outside of Dublin (where many services are), and those who live in rural areas. Consultation participants mentioned the larger costs of paying to travel to appointments, to employment, to pick up Disability Allowance (DA) (e.g., one person pays €30 per week to pick up DA), and a DPO noted the extra costs for d/Deaf people who have to travel longer distances to meet people they can socialise with;
* Fuel, electricity, and gas – some disabled people are not able to move or move much, so heating can be a huge cost. Charging equipment such as chairs, hoists, beds can have a significant impact on electricity costs;
* Necessary aids, appliances, and equipment - those which are not covered or fully covered under relevant schemes, and aids that are paid for privately as they are delayed too long in arriving through the public system;
* Assistive technology;
* Home adaptations; and
* Other costs including, but not limited to, addressing specific nutritional needs, necessary supplements, specific/adaptive clothing and shoes, higher insurance costs, nappies, parking charges in hospitals, and activities specifically for ‘special needs’ (these were noted as being expensive).

One person also talked about having to buy and use expensive items to make daily living possible, such as an automatic car, a tumble dryer, pre-packed vegetables, and grated cheese. Another noted that they will now incur an extra cost of disability because the machines for the new national Deposit Return Scheme for drinks containers are inaccessible, meaning they cannot claim back the deposits they pay on drinks.

### Current system of benefits and entitlements

#### Financial supports for people with disabilities

A recurring message from consultation participants was that the current provision of financial support for disabled people is inadequate, particularly with regard to the increase in the cost of living. Disability Allowance (DA), Invalidity Pension, Fuel Allowance, and Electricity Allowance were specifically mentioned as not being high enough. One participant stated that the Therapeutic Benefit Scheme was not adequate to cover the cost of hearing aids. A DPO representative and others noted that DA has not kept up with inflation, while others noted the level of DA is below the poverty line and has not kept up with wages. Quite a few participants expressed frustration with the fact that the initial COVID-19 Pandemic Unemployment Payment was higher than the DA payment.

‘During the pandemic the government provided 350 euros per week as min[imum] that people need to survive why is this figure not applicable to disabled people where research has confirmed we are struggling to survive.’

Participants talked about the challenges of paying rent and bills and gave many examples of material deprivation, with some participants not being able to afford heating, electricity, travel, cutting back on activities they enjoy, or not having any money to participate in activities they enjoy. One submission noted that some of their adult service users are dependent on food banks. The impact of not having enough money on people’s physical and mental health was noted. One participant stated: ‘You can’t go out if you don’t have enough money – affects your wellbeing.’

As well as challenges to daily life, the current level of allowances was noted as restrictive to people’s independence and ability to achieve their goals. Some participants reported they could only live on DA because they were living with their family or in a residential facility. Concern was expressed that many expenses were currently covered by people’s families and if/when the person moves into a home of their own or if the family is deceased, the DA will not cover the additional costs the person faces as a result of being disabled. One participant felt that it would be too hard to manage their money if they were to live independently on DA while trying to address the high cost of living. Another person who wished to upskill could not afford to pay for courses because there was not enough in their disability payment to allow them to save any money. Another participant noted:

‘As a person in receipt of invalidity pension and unable to work (not by choice) I find that the social welfare payments, while helpful, do not allow me to take part in events, travel, be as interactive in the community as I would like. Therefore, people with disabilities, unless they have a separate source of income, are isolated, are not really part of their community.’

While it was noted that one-off bonus payments to help address the increase in cost of living were appreciated, other consultation participants felt these were insufficient as they do not meet the actual cost of disability, and what is needed is a permanent income increase. It was also noted that employed people with disabilities are not entitled to these one-off bonus payments, and a participant felt such payments were an attempt to ‘pacify’ people with disabilities.

#### Means testing benefits and entitlements

Many consultation participants raised the issue of means testing benefits and entitlements for people with disabilities, such as DA and the medical card. People were very strongly against means testing these supports for disabled people and it was felt that the system is unfair and fosters financial hardship. Consultation participants offered a range of examples of how means testing has had a huge impact on their lives. For example:

‘I had to give up work as well and I did want to stay working. Now I’m down on money and living with the disease and expenses that incurs with the disease. But I am evaluated on my husband's wages, so I can't get a medical card, so my husband is trying to support me with this disability which I don't think it's fair because I am married. It's costing €12,000 extra a year but I can't get a medical card and I have a lot of doctor appointments and expenses, so I am not bringing in as much and it's costing a lot more money to living with this disease.’

Another person explained that they had to return to work because of means testing, even though this was extremely challenging:

‘I was approved for disability allowance, but because my partner works full time, my pay rate was miserable, and we are not even married. I had to take up employment to cover the costs of rent, bills, food, etc. I only work part-time because that is the best that I can do with my condition. Even working part-time can be torture for me due to my condition, I suffer a lot sometimes and I have been very close to quitting on many occasions due to how difficult it can be for me.’

One person in the early stages of a progressive disability outlined the worry caused by means testing for their future:

‘…at present I don't need formal supports or aid, I also under current system would means test above some supports. This is an issue and creates significant financial worry for me for my future.’

Means testing was seen as penalising a family for having a person with a disability and penalising disabled people who were embarking on relationships, or who would like to move in with their partners or marry them, as one participant reported:

‘The current means test for disability allowance means I cannot live with my partner, it’s like we're not allowed to love anyone.’

Consultation participants also felt that means testing is disabling people further, making them reliant on whoever is earning. Participants expressed great concern about this forced dependency, whether it is an individual who cannot get a medical card because of their parents’ incomes or an individual with a disability who is reliant on their partner’s income. There were also concerns raised about the power dynamic of these kinds of relationships, with people flagging how such situations can leave people at risk of abuse:

‘A disabled person that wishes to marry or live with their partner will lose their autonomy and they become the financial responsibility of their partner. This is not a lifestyle choice and definitely not a dynamic conducive to a healthy relationship... for either person in the relationship. Disabled people are vulnerable to becoming trapped in abusive relationships as a result, surely this is a human rights violation.’

Research suggests that disabled people are more likely to experience abuse than those without disabilities, and forcing financial dependence on a partner can not only cause problematic power dynamics, but also make leaving a relationship particularly challenging. This was noted a number of times by consultation participants with regard to women with disabilities who may be in abusive relationships.

#### Benefits and entitlements applications

Consultation participants used terms like ‘battle’, ‘fight’, ‘degrading’ and ‘frustrating’ when referring to applying for supports. A DPO representative noted that people with disabilities find applying for supports onerous, distressing, humiliating, and another DPO representative noted that in disclosing so much personal information to State officials, you lose your right to privacy. One person stated: 'when you apply for disability you are treated unbelievably bad, like you are a robber’.

The application process was described as long and complicated. One person expressed issue with the transition from the Invalidity Pension to the Partial Capacity Benefit. Consultation participants referred to delays in receiving responses, meaning time without income and time without being able to access secondary supports. One person noted:

‘The DA payment qualification and requalification system is not responsive and immediate enough as is currently setup- it means people applying or reapplying endure severe financial hardship with extremely prolonged periods of no income while their case is being assessed, reassessed or in appeal.’

It was noted that regular reviews caused a lot of stress and anxiety to people with disabilities.

Other people had issues with the eligibility criteria for supports, for example:

‘Assessment of eligibility for disability allowance is not fit for purpose - it excludes those with disabling chronic illness who may have otherwise functioning mobility, limbs, speech, hearing and sight. Eligibility must factor the real risk of health deterioration as qualifying condition for disability payment.’

Some consultation participants felt that unless you have very complex needs you do not get DA. A number of participants were frustrated with the fact that when someone with a disability turns 65 or 66, they are suddenly not eligible for disability supports. Consultation participants expressed concern about the eligibility criteria for the medical card, and it was clear from discussions how valuable the medical card is to people. Other consultation participants felt that the eligibility criteria for the Primary Medical Certificate and Long-Term Illness card are too restrictive.

Several participants referred to challenges when supports were contingent on one other; for example, if you are not eligible for the medical card, you are restricted from accessing other supports, and if you move from Invalidity Pension to Partial Capacity Benefit in order to work you lose a lot of other benefits e.g., Carer’s Allowance.

Quite a few people questioned the assessment of eligibility for supports. They felt that what medical professionals had said in their applications had been dismissed, that it seemed common practice to refuse people on first application but provide support on appeal, and decisions about who gets DA can seem arbitrary, with the anecdote of two people in the same situation getting differing decisions.

#### Specific issues for the Travelling community

One DPO noted in the consultation the importance of intersectionality when considering the economic situation of people with disabilities. Some consultation participants from the Travelling community felt that they wait longer than the settled community to access DA. Another person referred to the negative impact on the Traveller community when they have to submit photos of their homes and continue to appeal to get basic entitlements. An example was given of a Traveller family who had to involve their local TD to address delays in accessing social protection benefits – but it was noted that not all Traveller families are able to navigate the complex and difficult benefits system.

### Feedback on the Department of Social Protection’s Green Paper on Disability Reform

DPOs and other consultation participants were strongly against the proposals in the Department of Social Protection’s Green Paper on Disability Reform.[[20]](#footnote-21) A number of people referred to it as being a copy of the UK approach, which one participant believed to have led to poverty-related death and suicide.

DPOs and others had concerns about the overall approach of the Green Paper, calling it paternalistic and noting that it does not mention the UNCRPD. It was felt there was a lack of involvement of the voice of people with disabilities in these proposals and that the consultation process was inaccessible. These fundamental issues appeared to undermine trust in the proposals. A number of DPOs wanted clarity on whether the consultation on the Green Paper would inform the National Disability Strategy, or vice versa – and ultimately whether DSP or DCEDIY would be responsible for the outcome. A few participants had concerns about the Green Paper proposals being considered before the Optional Protocol was ratified. One participant also noted their frustration that these proposals are being put forward before issues with education, health and social care services and supports have been addressed in Ireland.

Consultation participants described the feelings an approach like the one proposed by the Green Paper provoked in them. There were strong fears of payments being cut or reduced. A participant noted that categorising people into tiers can be traumatising for many people with disabilities, while another felt it was demeaning. It was noted that the expectation that people should be looking for work speaks to fears that disabled people are continually judged by the State. This feeds into a lack of trust and confidence in the State, and impacts people’s feelings of safety and security. There was a question whether the Green Paper proposals would cause disharmony amongst people with disabilities – referring to the fact it might be challenging for autistic people to be appropriately assessed compared to someone who is deaf.

Some consultation participants had concerns about the practicalities of the tiered approach proposed in the Green Paper, querying how this could work. The main concern about the tiers from DPO representatives and others was that the levels of payment proposed for each tier are not considered adequate to enable a decent standard of living in Ireland. The highest level of payment proposed (€265.30 per week) would be below the poverty line (€318.53 per week for an individual[[21]](#footnote-22)) and these payments would not address the cost of disability. A participant felt a problematic assumption underpinning the Green Paper was that once you are in a job, the cost of disability is your problem, and you have to absorb the extra costs. It was also noted that the Green Paper refers to the extra cost of having a disability to be on average between €9,000 and €12,000 - whereas the Indecon report states €12,000 is not the upper limit of the cost.

There were two positive comments on the Green Paper in this consultation, one person felt the proposal is quite good and another noted that at least it establishes an increase in payment is needed for people with disabilities.

## 5.9.2 Proposed actions and solutions

Consultation participants provided many suggestions for how challenges regarding financial independence and security for disabled people in Ireland could be addressed in the new National Disability Strategy. These included suggestions to address poverty levels of disabled people, measures to address the cost of disability, and proposals to improve the financial situation of disabled people through reforms to the current system of benefits and entitlements.

### Level of poverty in people with disabilities in Ireland

* Develop a specific poverty reduction strategy for disabled people, addressing the inadequacy of social protection supports and the full extra cost of disability.

### Cost of disability

* Acknowledge and address the extra cost of disability as a priority;
* Ensure the cost of disability is understood and responded to by all relevant government departments;
* Develop a cross-governmental Action Plan to address the cost of disability;
* Implement the recommendations of the Indecon Cost of Disability report (with adjustments for inflation) as a priority (contribution from DPOs and others);
* Introduce a permanent, non-means-tested, non-taxed cost of disability payment, which is separate to social welfare payments (contribution from DPOs and others);
* Take a life-cycle approach to assessing and meeting the costs of different types of disability;
* Address the costs of services, supports, equipment, and medications:
  + Give people free long-term service and supports,
  + Regulate pricing of private therapies,
  + Provide funding for those who have to seek private assessments,
  + Widen scope of cover for medications,
  + Review medication charges,
  + Give people free hearing aids,
  + Expand the loan/rental scheme for stair lifts/hoists,
  + Make equipment and treatment supports fully tax deductible,
  + Create a special fund for equipment, technology and other essential assistive aids and appliances for people with higher support needs and their families,
  + Provide supplements to support those who have to pay for equipment, aids and appliances themselves, including those who work,
  + Cap hospital parking charges to a nominal amount per day or abolish them for inpatients or those with appointments.

### A basic income for people with disabilities

* Introduce a basic income for people with disabilities. Suggestions included:
  + An index-linked income matching the Minimum Essential Standard of Living considering, and covering, the extra Cost of Disability,
  + A universal basic wage system,
  + Universal income with the Wage Subsidy Scheme heavily promoted and expanded.

### Current system of benefits and entitlements

#### Eligibility for benefits and entitlements

* Make eligibility for benefits and entitlements more inclusive;
* Give full recognition to all people with disabilities, significant/chronic illness and those with additional needs within the term ‘Disability’;
* Give automatic entitlement of a medical card to all people with disabilities (contribution by DPOs and others);
* Expand eligibility of the Primary Medical Certificate to include more people with disabilities and with chronic illness, and for example, to those with functioning limbs intact but have other significant health challenges such as cystic fibrosis where lung impairment is significant or those immuno-suppressed or immune vulnerable and precluded from risk of public transport cross-infection;
* Give all d/Deaf people DA;
* Expand eligibility for the GP Visit card;
* Expand eligibility for the Long-term Illness Card;
* Extend financial aid, such as the Household Benefits Package and Fuel Allowance, even for those in shared accommodation; and
* Remove the PRSI condition for Illness Benefit.

#### Advice and information for people on benefits and entitlements

* Improve the advice and information for people on benefits and entitlements;
* Give information in a way that both children and adults can understand – including for example, Easy Read and ISL; and
* Reduce wait times for Citizens Information Centres by providing additional services.

#### Application process for benefits and entitlements

* Improve the communication between the Department of Social Protection and families;
* Make the process shorter, easier, accessible, streamlined, more responsive to the dynamic needs of people whose abilities fluctuate;
* Address any backlog in applications;
* Improve the application form for DA to ensure it is asking for all the information that is needed;
* Make the appeals process easier;
* Increase awareness among Deciding Officers of the importance of listening to those who are experts in their own disability and of the validity of opinions from GP and medical specialists;
* Make transitions automatic/immediate, e.g., moving from supports as a child to an adult and DA requalification;
* Explore and address any differences found between application processing times for members of the Travelling community and others; and
* Reassess applications only when necessary. People with permanent disabilities should not have to be reassessed to see that they still qualify for disability payments.

#### Financial supports for people with disabilities

* Increase the level of financial support for people with disabilities to enable a decent standard of living as a priority;
* Increase the levels of social protection payments to people with disabilities, bringing levels to a living wage; and
* Be mindful of how proposals with tiered payments will be received. Some participants were in support of tiered payments, while others were quite strongly against them. For tiered support, it was suggested to pay more to those with extra expenses due to their disability or to those who are unable to go to work.

#### Means-testing benefits and entitlements

* Remove means testing of supports including DA, the medical card, electricity and fuel allowances or means test individuals with disabilities, not households; and
* Review means testing of all payments in terms of equity.

#### New benefits and entitlements

* Introduce a personal tax credit for people with disability/chronic illness or injury;
* Introduce an allowance for anyone with a disability (employed or not) to spend on what they wish;
* Provide an allowance for children and young people with disabilities to facilitate them to try out activities in their communities;
* Introduce a new social payment to support anyone out of work /self- employment who is sick but has no/insufficient PRSI contributions for Illness Benefit and no income from employment/self-employment;
* Introduce a cost of disability allowance towards broadband, as disabled people have a particular need for connectivity; and
* Make linkages across supports. For example, if you are on disability payments, you should automatically get a medical card and free travel pass for an extended period of time.

# 5.10 Transport and mobility

## 5.10.1 Context and challenges

While there was a specific focus group discussion on transport, issues related to transport came up in almost all focus groups, consultation meeting discussions and in survey responses. It was also mentioned in several of the submissions. The contributions were largely given in the context of the challenges that limited transport options posed to disabled people, including independence, accessing education and employment opportunities, and being included in their communities. As one participant summed it up:

‘More accessible transport is needed for all people with disabilities to be able to fully participate in lives of their choosing; this needs to be across all areas, including public transport systems, better and more transport for disability services and private vehicles for people with disabilities.’

Issues with needing transport to attend medical appointments were raised, and an organisation who participated in the consultation reported that they frequently receive requests for transport for hospital appointments. There were several references to Article 9 (Accessibility) of the UNCRPD and while Article 20 (Personal mobility) was not specifically mentioned, the concept of freedom of movement was referenced, with one person calling it a fundamental right under the UNCRPD. Many consultation participants also spoke of a lack of joined-up thinking in transport planning.

### Public transport

#### Physical access to public transport

Physical access to public transport was raised frequently as a challenge. Participants reported difficulty getting to or using a bus stop or rail station. They described situations where there were no footpaths, narrow footpaths, poorly maintained footpaths, inaccessible bus stops, and no shelters at bus stops. As one participant said: ‘No matter how good the public transport is, it’s no use if we can’t get to it.’

Inaccessible buses were mentioned as a frequent challenge, with several participants saying they could not navigate the steps and some having ‘ground access’ as opposed to kerb access. The lack of space on some buses for mobility scooters, for more than one wheelchair, and limited seating for disabled people was also raised. A DPO representative reported that some outsourced public service routes do not provide accessible transport, with an example given of Dublin Express from Heuston station to Dublin airport. This participant also noted a requirement to book days in advance. Another DPO representative recommended – ‘Stop buying inaccessible buses’.

Prior notification for ramp access on intercity train services was noted as a key issue impacting a person’s ability to be spontaneous or more independent when travelling. Unstaffed stations were also reported to cause challenges. Some participants, for example, complained that even when notice was given that assistance would be needed, sometimes the staff member did not show up. The number of wheelchair spaces and challenges with booking a wheelchair spot were also raised. Lifts being frequently out of order at intercity train or dart stations was reported to significantly impact travel, as one participant said:

‘The frustration of pre-booking and giving prior notice for ramp access can be deepened by often arriving at a station to find the lift is out of order.’

Another participant mentioned the overcrowded Luas where it would not be possible for a person using a wheelchair to board and how it may be too noisy and crowded for someone with sensory issues to travel.

#### Communication barriers using public transport

Members of the d/Deaf community, including a DPO, noted that audio announcements on public transport and at airports are frequently being made without the information visible on screens at the same time. They reported that some d/Deaf people pay the maximum fare on Dublin Bus because of difficulties communicating with bus drivers where they want to go. There are particular difficulties in communication when a train or bus breaks down. This is more of an issue for Deafblind people, and it was noted that they may need access to personal assistance for public transportation.

People with visual impairments, including a DPO representative, reported that sometimes the speakers on public transport do not work, which is very challenging for a blind person.

There was some praise for the JAM card[[22]](#footnote-23), particularly for people with invisible disabilities.

#### Availability of public transport

The majority of consultation participants who raised issues related to transport felt that public transport needed to be more available, reliable, and frequent, particularly in rural areas. The limited transport options in rural areas were reported to affect social inclusion, community participation, independence and education and work opportunities. The impact on specific groups such as rural women and d/Deaf people were specifically noted. For example, one participant linked mental health issues and isolation to the lack of transport in rural Ireland.

Some participants, including a DPO, welcomed schemes like Rural Link and Local Link but felt that they needed more funding and better linkage with other transport services. The point was also made that these journeys can often take longer. The lack of public transport causes some people to take taxis to work or appointments and that has an impact on their income. Many people said they just cannot afford taxis, and some said the bus stop is too far away. As one younger participant said referring to the lack of availability and accessibility of public transport- ‘I’m sick of sitting beside my mother in the car’.

There were mixed views about BusConnects in Dublin. Some participants said that, although it had been difficult to learn the new routes and numbers, they welcomed the improvement in the frequency of services. Having a good bus and train service was an essential support for people with disabilities to use their communities. One person noted that when changing to the second bus there is no guarantee that there will be space on that bus, and so there can be a lot of waiting. A DPO participant noted that the Dublin Bus timetable was inaccessible and another that the blue disabled buttons on buses often do not work. There was another comment that BusConnects had led to a reduction in services.

#### Affordability of public transport

There were criticisms in relation to the booking systems for public transport, with some participants finding these difficult. For example, a number of participants raised the issue of having free travel but having to pay a booking fee. One DPO representative noted that this is now being reviewed by Bus Éireann and another person reported that this was illegal under EU law.

One participant highlighted that refugees with a disability have a disability travel card but asylum seekers with a disability do not. Without this additional financial aid, transport can be very difficult for disabled asylum seekers. Another group affected by cost are d/Deaf people who may not live close to other d/Deaf people and therefore may have to travel for social connection.

#### Active travel

Participants reported a lot of challenges with active travel policies (walking and cycling). Participants said that these concerns have been raised at other meetings, including with transport stakeholders but they felt that they have not been listened to and emphasised the need for accessibility to be a constant theme. Many of the concerns raised were by DPOs and were largely to do with safety concerns, such as:

* the lack of differentiation between cycle lanes and walkways,
* the requirement to cross a cycle lane to get to a bus stop (i.e., floating bus stops),
* dangers associated with contra flow bus lanes and cycle lanes,
* the replacement of tactile ground with tarmac (e.g., after roadworks),
* a sense that cycling and cycling infrastructure seem to be prioritised over pedestrians,
* raised crossings where everything is on one level,
* the increasing use of footpaths by bikes and electric scooters,
* an increase in aggression by cyclists and scooter users,
* concerns that electric vehicles are too quiet and can therefore put someone with a visual impairment who relies on sound at risk.

Pedestrianisation of streets was reported as presenting a challenge for people who need door-to-door transport such as people with vision impairments, older people, and people with mobility issues. For example, in a pedestrianised area, it is not possible to pull in a car to drop someone off. Street furniture was also reported to pose a challenge for people with visual impairments.

#### Legislation and standards

Participants felt that the National Transport Authority (NTA) was not using all their powers to make public transport accessible under section 13.1 of the Public Transport Regulation Act. There was a sense that the NTA was not fully accountable. It was also reported that different bus providers have different policies and procedures which make travelling difficult. As one participant remarked:

‘So we end up with hodge podge designs based on various peoples’ interpretations of accessibility. We need more meaningful co-design of infrastructure.’

### Private transport

#### Taxis

Taxis were reported by participants to be unreliable, unavailable, and unaffordable. This was particularly so at peak hours and because many taxis had contracts with companies that were considered more lucrative than picking up disabled passengers. Participants reported that while demand for accessible taxis has increased, supply has not. West Clare and Cork were mentioned as being notably bad for accessible taxis. A participant noted that it is particularly costly for people who have frequent hospital appointments and travel by taxi.

There was also an issue raised around the suitability of some accessible taxis. One person reported that ramps are not always suitable or safe, many drivers will not use the restraints, and some of the cars are too small. This person also reported that if someone gets a grant for a wheelchair taxi, they are supposed to do training and take a certain number of disabled fares per month but that this often does not happen. A DPO member said that it is difficult for a visually impaired person to get the number of a taxi to make a complaint, for example, if they refused to take a guide dog.

#### Specific mobility schemes

There was much discontent expressed about the ending of the Motorised Transport Grant and the Mobility Allowance. Participants reported that the lack of Mobility Allowance led to social isolation and to people struggling to get to hospital appointments and creating a dependency on family, friends, or neighbours. With regard to the Motorised Transport Grant one participant said:

‘As a result of gaining my own transport I am now in fulltime meaningful employment, which is a great privilege, but I wouldn't have got that start without the motorised transport grant and I strongly feel this should be reinstated for people that live rurally.’

Several participants, including DPOs, talked about the Disabled Drivers and Disabled Passengers Scheme, specifically the restrictiveness of the criteria for obtaining aPrimary Medical Certificate necessary to receive tax relief. The lack of an appeals process was described as ‘inexcusable’. One participant felt that current schemes for disabled drivers are for those who have good income and savings and that they do not support those on welfare payments.

#### Private car

One participant reported that electric vehicles are much more suitable for disabled people as they are automatic, but there are no electric charging bays that are accessible for disabled people. Another person said that they can’t drive a manual car but can drive an automatic, however they can’t afford an automatic. Some participants felt that they can’t be without their car due to their condition (e.g., fatiguing easily) and felt there should be more supports available. A carer noted that her family and her adult daughter can’t go anywhere without a car. They had to buy a special seat that cost €2,500 without support. A DPO member described the UK Motability system,[[23]](#footnote-24) where you can lease a car or van. Members of a DPO also spoke about how intercoms, for example those used in car parks, are neither accessible nor d/Deaf friendly. Another issue raised was that a d/Deaf person cannot use SOS phones on motorways. One participant reported limited accessible parking bays at train stations.

### Voice of disabled people

One DPO emphasised the need for representative voices to be heard and prioritised (i.e., DPOs) in decisions about transport. This participant complained that the NDA was taking up a DPO seat on the Department of Transport’s Accessibility Consultative Committee. This person also noted that the NTA have a partnership with the Wayfinding Centre, which is not a DPO.

There was concern expressed from one participant that disabled people were restricted from sitting on State boards (i.e., related to transport) as if they were in receipt of the Invalidity Pension as they are not allowed to do any paid or voluntary work. One DPO member felt that the government was not prioritising disabled people and quoted General Comment 7 of the UNCRPD to make their case. They also noted that the NTA does not have a disability group, only a transport user group and many of the users are service provider organisations, with no DPOs represented. A further point emphasised that there is no person in the planning offices of local authorities who is dedicated to disability.

### Attitudes and awareness

Many participants talked about the attitudes of drivers and other staff in public and private transport services. While some drivers were complimented on providing a good service, such as giving more time to a person with a disability or calling out the bus number to a person who is blind, there were lots of comments about poor service. For example, some drivers were reported as driving off rather than waiting for a person with a disability or as not waiting until a person with mobility issues is seated before moving off. According to participants, other drivers will not stop and call the route number when it is clear there is visually impaired person at the bus stop.

Specific examples on a lack of awareness of disability by transport staff were provided. An example was given where a d/Deaf traveller sought assistance in an airport and was offered a wheelchair rather than appropriate supports. Another example was reported where a taxi refused to take an adult with a disability saying he would not take responsibility for “a child”. Finally, there were concerns from some participants that an airline company was restricting the number of disabled people on flights.

## 5.10.2 Proposed actions and solutions

Consultation participants provided many suggestions for how issues with transport and mobility could be addressed in the new National Disability Strategy. These suggestions are listed below:

### Transport system

* Create and implement an emergency response plan for ensuring that public transport is treated as an urgent issue to be addressed;
* Conduct a review on the accessibility of public transport;
* Implement a whole of journey approach to transport to ensure there is accessibility from the moment a person books their ticket until they arrive at the destination;
* Do not separate transport initiatives across different government departments;
* Unify all transport policies as changes are often made with no communication;
* Introduce legislation to make sure transport policies are disability proofed through DPOs and future proof transport services; and
* Disability proof all transport strategies, not just those for people with disabilities.

### Public transport

#### Physical access to public transport

* Implement a Universal Design approach to all licensed passenger transport providers and in the procurement of fleets to ensure accessibility;
* Strategically look at public transport stock and associated infrastructure;
* Design all public transport for easy on/off access (similar to the LUAS) to promote independence and eliminate reliance on assistance with ramps;
* Make ticket machines more accessible;
* Put customer service agents on all trains;
* Ensure lifts are working in all stations (DPO contribution);
* Increase spaces on buses for those with disabilities;
* Commission buses with at least two wheelchair spaces;
* Provide better infrastructure such as kerb access at bus stops; and
* Reopen the Western Rail connections.

#### Communication issues related to public transport

* Ensure audio and visual announcements are made on all public transport; This is particularly important where there are unexpected interruptions to services (DPO contribution);
* Consider video messaging with captioning, visual icons, and ISL translation on trains and buses (DPO contribution);
* Improve real time information on lifts at train and DART stations;
* Provide more accessible customer services in train stations and airports for people who are d/Deaf or hard of hearing;
* Streamline and simplify the booking process (in person and online); and
* Make ticket machines more accessible.

#### Availability of public transport

* Improve transport services and increase investment in transport in rural areas;
* Introduce private shared transport instead of taxis;
* Ensure asylum seekers with disabilities are located within areas that are easy to get access to basic needs of their daily life;
* Collaborate with regional authorities, such as Local Link, and educational institutions to identify and address specific transportation needs of students with intellectual disabilities;
* Introduce a special bus service for people with disabilities in rural areas that can be booked to take them to certain places and events;
* Introduce a transport allowance, drawing on the principles of the Personal Independence Payment in Northern Ireland to reduce the barrier for people, particularly those with a visual impairment to engage in sports and physical activity;
* Provide access to transport to local facilities like beaches, parks and forests; and
* Fund transport training for young people moving into post-school options.

#### Affordability of public transport

* Consider introducing a free travel pass for d/Deaf people (DPO contribution);
* Remove restrictions on the free travel scheme during peak times; and
* Refuse private bus contracts if they deny access to services for people with free travel pass.

#### Active travel

* Disability-proof new active travel schemes through DPOs;
* Review what is working well, for example, consult the Design Manual for Urban Roads and Streets (DPO contribution);
* Eliminate floating bus stops;
* Provide safe parking spaces away from cycle lanes; and
* Separate cycling and walking infrastructure.

#### Legislation and standards

* Ask the National Standards Authority of Ireland to develop, with DPOs, a code of practice and standard for public transport;
* Introduce mandatory accessibility standards (existing ones are voluntary); Public transportation providers in all regions should meet accessibility standards;
* Increase communication/linkages between guidelines/standards and different responsible bodies, for different types of travel (e.g., cycle tracks and bus stops);
* Amend legislation so that people/buggies are required to move out of a wheelchair space on a bus and support the drivers to enforce this;
* Apply sanctions to transport providers where appropriate;
* Give NDA an enforcement role with National Transport Authority (NTA) to bring in Universal Design and best practice (DPO contribution);
* NTA should make all forms of public transport accessible using existing legislation or developing new legislation as needed (DPO contribution); and
* Introduce regulations for airlines with regard to access for disabled passengers.

### Private transport

#### Taxis

* Make it a priority for wheelchair accessible vehicles to collect wheelchair users;
* Introduce standardised taxis with standards of accessibility for all taxis in a realistic timeframe (DPO contribution);
* Ensure the NTA use their powers to increase accessibility (e.g., ensure that all taxis are accessible);
* Introduce wheelchair-specific taxi bays (DPO contribution); and
* Increase flat rates as fares vary among taxis.

#### Specific mobility schemes

* Reinstate the Motorised Transport Grant to support people to buy a car;
* Increase flexibility in the Disabled Drivers and Disabled Passengers Scheme Primary Medical Cert and ensure faster response times (DPO contribution);
* Introduce an appeals board for the Primary Medical Certificate;
* Remove the condition of having to have a Primary Medical Certificate to qualify for VRT reduction and fuel VAT exemption;
* Increase the value of the VRT and VAT exemption on large wheelchair accessible vehicles used for power wheelchairs;
* Remove adapted vehicle requirement for toll charge exemption - expand scheme to include those people with disabilities/chronic illness not currently defined within existing Primary Medical Certificate;
* Make it easier to get a wheelchair adapted vehicle;
* Invest in more adaptive vehicles;
* Reinstate the Mobility Grant;
* Introduce a grant to provide transport for specific events (DPO contribution); and
* Provide people with disabilities with a number of taxi vouchers each year which they could use for community activities.

#### Private vehicles

* Think more broadly about supports for private vehicles;
* Expand eligibility criteria for tertiary private transport supports, such as free parking, free tolls, and fuel allowance for those dependent on private transport;
* Consider returning VAT for blind people with cars;
* Consider fuel subsidies for people who may not need a car adaptation but have mobility issues so are car dependent;
* Introduce a reduction on electric vehicle charge cost in addition to VRT reduction for people with disabilities/chronic illness;
* Have more disabled parking spaces and make the process to get a disabled badge more accessible;
* Increase parking for older people especially at hospital and consider free hospital parking for people with disabilities and chronic illnesses;
* Make learning to drive more accessible by ensuring:
  + A quiet room for people with autism to take the driving theory test,
  + More specialist driving instructors for people with autism and people with intellectual disabilities and other disabilities,
  + Help for people with disabilities to pay for driving lessons and insurance,
  + People with disabilities are taught about driving in school like other teenagers.
* Add an electric charging point at every disabled parking bay;
* Make electric vehicles more available for disabled people as many are automatic and easier for some disabled people to drive;
* Protect/exempt disabled people from any climate action relating to vehicular congestion in towns and cities; and
* Ensure shared vehicles (e.g., Go Cars) have accessible options.

### Voice of disabled people

* Have meaningful consultations on transport that prioritise DPO views; and
* Organise an NDA conference on transport that includes DPOs, accessibility officers, taxi companies.

### Attitudes and awareness

* Raise disability awareness of all staff associated with public and private transport and ensure they are trained in supporting disabled people;
* Increase messaging to encourage people on buses and trains to give up their seat if they see someone with a disability;
* Encourage all drivers to be patient; and
* Support disabled people to drive for as long as they can.

### Other issues

* Ensure tour buses have disabled access to promote tourism;
* Introduce a centralised and accessible travel website and app for all public transport services;
* Provide all disability services with transport services that can be easily deployed for all people with disabilities to be picked up and dropped home from services;
* Provide an automatic right to transport provided to and from home to service locations;
* Support organisations like IWA, CILs, Enable Ireland etc., to provide accessible transport for individual and out of hours journeys; and
* Facilitate people to use the HSE services which are closest to their home to avoid travelling long distances.

# 5.11 Culture, recreation, leisure, and sport

## 5.11.1 Context and challenges

It was evident during consultation discussions that opportunities for leisure and recreation, and access to the arts and culture had a positive impact on people’s quality of life, as well as reducing loneliness. Although this theme was mentioned less frequently than other themes, participants identified barriers to participation and an inconsistent approach to addressing the exclusion of people with disabilities within these areas.

Consultation participants indicated that they were involved with several sporting and social organisations. They were keen to do more of the activities they enjoyed. However, there was a call for more meetups and opportunities to develop relationships with other disabled people under the social model, rather than in charitable or medical contexts.

Children and young people with disabilities enjoyed access to age-appropriate activities alongside disabled and non-disabled peers. They highlighted the importance of continuous support to engage in these activities, with one young person giving the example that a community organisation had forgotten about their disability over the long-term. Neurodiverse children in particular experienced challenges going to new places and meeting new people. They welcomed the idea of more taster sessions or showcases, to try out new hobbies without being forced to make a huge commitment. As one child stated: ‘I need a welcome put out…I would find it hard to just go and join something.’

### Inaccessible facilities

People with disabilities reported being denied opportunities for leisure and recreation due to inaccessible facilities within sports clubs, entertainment venues, bars, hotels, and town centres. Restaurants which claimed to be wheelchair accessible were deemed unsuitably cramped and one consultation participant highlighted a visit to a swimming pool with staff who were untrained in the use of equipment. Consultation participants emphasised the need for sensory-friendly spaces in restaurants, theatres, and other social and cultural venues.

One participant noted that she was ‘interrogated’ about her disability when visiting attractions. She proposed the following solution:

‘If we could get a universal disability card to gain free access granted by OPW for example. For free group events round the country (…) we never end up going and getting a day out.’

### Transportation

Transportation was recognised as a major barrier to participating in sport and other physical activities. One consultation participant expressed a desire to get more active in the community but was hindered by parental concerns about road safety.

### Specific barriers for the d/Deaf community

A DPO representative raised barriers experienced by the d/Deaf community to participating in cultural, social, and sporting events, including a lack of subtitles at weekend film screenings, an absence of interpreters at social events, and difficulties playing with or participating in hearing team sports or competitions. This resulted in social isolation from the local community without considerable effort on the part of the Deaf person. As one focus group member explained: ‘The onus is always on Deaf people to get involved.’

### Specific challenges for LGBTQI+ disabled community

There was recognition of the need for more inclusive activities within the LGBTQI+ community. Participants called for community activities which are less busy and/or intimidating, such as dog walking or running. Notably, there was a reported dearth of social groups for LGBTQI+ people over 35 years old outside Dublin. The lack of accessible LGBTQI+ community spaces meant that disabled members felt invisible and isolated. One visually impaired participant felt alienated from making social connections due to their difficulty in recognising faces.

## 5.11.2 Proposed actions and solutions

Consultation participants proposed a variety of actions and solutions to address challenges to accessing culture, leisure, recreation, and sport within the National Disability Strategy. These include infrastructural changes, increased regulation of the hospitality industry and more funding for community groups.

### Communication and information

* Continue the ISL voucher scheme which provides free access to ISL interpreters for a variety of events, services, and activities (DPO contribution);
* Encourage social venues to offer photographs, videos, or virtual tours on their website alongside accessibility information to reduce anxiety for visitors;
* Provide more outdoor events and information about health and safety recommendations (e.g., masking) to accommodate Covid-19 conscious attendees;
* Encourage venues to provide phone services for booking theatre and concert tickets and to families/groups to sit together in disabled seating zones;
* Encourage venues to provide additional accessible and autism-friendly performances in theatres, cinemas, and other arts spaces; and
* Invest in a national access software platform that would allow cultural venues to mainstream and tailor booking systems for audiences with disabilities.

### Physical environment

* Seek a commitment from the hospitality industry to ensure the availability of affordable, fully accessible accommodation options, including electronically adjustable beds;
* Provide Changing Places toilets in shopping centres, hotels, cinemas, and swimming pools;
* Improve the design of playgrounds, sport and leisure facilities to make them disability-friendly (e.g., bowling alleys and climbing centres to ensure they could be used by those who are visually impaired). This would involve giving more consideration of colours and textures, gradients, spacing and adapted equipment;
* Improve access in places such as beaches, so people with disabilities can use the beach and experience the water;
* Build more venues with the infrastructural capacity to support the creation, performance, interaction with and exhibition of works by disabled artists; and
* Prioritise an analysis of the accessibility of creative spaces, identifying those that are inaccessible or not sufficiently accessible; invest in retrofitting such spaces. Identify and support accessible, non-traditional arts spaces.

### Peer support

* Support the establishment of more community groups to enable people with disabilities to meet like-minded individuals who share similar hobbies/interests;
* Improve access to local sports clubs to ensure that people with disabilities can join different teams and be valued members, including adaptive sports for specific impairments;
* Provide activities for young people which are not based around alcohol or sport e.g., board games, book clubs, cafés; and
* Maintain and improve funding for social and support groups.

### Personal assistance and home care

* Provide more support to disabled people to engage with wellbeing services e.g., gyms; and
* Provide more support for adults with disabilities who live with their parents to take part in weekend activities.

### Transport

* Introduce a transport allowance to facilitate access to social communities and health and fitness initiatives/centres, drawing inspiration from the principles of the Personal Independence Payment in Northern Ireland.

### Encourage and enhance participation

* Increase funding for community-based organisations and service providers to adapt and include disabled children;
* Hire inclusion support workers to enable children and young people to participate in mainstream activities e.g., after-school sports;
* Adopt a life-long approach to culture, leisure, recreation, and sport, with a range of activities available for young and old with various impairments;
* Distribute funding for resources and supports equitably, to ensure participation at a regional level;
* Provide funding to make LGBTQI+ resource centres and community spaces accessible; prioritise accessibility spanning physical infrastructure, digital spaces, and the availability of information;
* Develop accessible multipurpose community spaces and sports facilities to provide a social outlet for those experiencing isolation; and
* Employ disability advisors for local community events.

### Other

* Regulate industry standards for health and safety during community activities e.g., a consistent approach to the use of bouncy castles by children with visual impairments who wear glasses;
* Invest more in capital costs for individuals to avail of or modify equipment to enable equitable participation in the arts;
* Put in place an adequately resourced funding and support infrastructure, developed by and with DPOs and disabled artists at every stage, to assist professional artists with disabilities to develop ambitious, critically reflective, energising, and sustainable artistic practices and careers; and
* Recognise reasonable adjustments in leisure/social activities.

# 5.12 The justice system

## 5.12.1 Context and challenges

While justice was not a prominent topic during the consultation, a statutory body and a civil society organisation provided detailed submissions on disabled people in prison custody.

### Accessibility of the legal system

Some consultation participants noted that disabled people may encounter challenges in navigating the legal system, understanding their rights, finding appropriate legal representation, and accessing advocacy services. There were also reports of communication and information barriers when accessing legal services, including complex written forms, challenges accessing an ISL interpreter, and a reluctance by legal professionals to accommodate communication preferences.

The importance of accessible legal aid and court services was underscored, with one submission noting that the family law courts, and childcare proceedings are inaccessible to some parents with disabilities, which can lead to disengagement from legal supports. The same submission also highlighted that ‘parental mental illness and cognitive disability are common among parents before the courts’.

### Awareness of disability

Some consultation participants asserted that justice professionals lack understanding of the needs or rights of disabled people, with a DPO citing an example of a Garda requiring a Deaf person to make a statement without the assistance of an ISL interpreter.

### The prison system

Key concerns identified in two submissions related to the overrepresentation of disabled people within prison custody, the lack of explicit focus on both people with disabilities in prison and people with psychosocial disabilities within previous disability strategies, the lack of robust data on the nature and prevalence of disability in the Irish prison system, inadequate screening tools in the Irish Prison Service, and the lack of accessible and inclusive physical environments and supports in prison.

Other challenges encountered by people with disabilities in prison related to difficulties accessing timely, appropriate, and accessible healthcare, complying with prison rules and discipline, and reintegrating in their communities after prison. Some of the specific challenges faced by people with psychosocial disabilities in prison were also spotlighted, including that prison settings cannot be considered as therapeutic and the lack of timely transfers from prison to the National Forensic Mental Health Service. The barriers faced by children with disabilities interacting with a parent in prison were also raised, with the sensory garden in Wheatfield Prison identified as a welcome initiative to better meet the needs of these children.

### Mental health and the criminal justice system

The importance of diverting people with mental health issues away from the criminal justice system, alongside the availability of a comprehensive suite of mental health interventions to enable this were spotlighted. While police custody was highlighted as an entry point to the mental health system, it was noted that concerns have been raised with respect to the quality of screening for mental health issues in Garda stations, the adequacy of supports, training of Gardaí in this area, and pathways to care from Garda custody.

### International protection

One submission noted that disabled people seeking asylum can face barriers accessing refugee status determination processes. These barriers include procedural barriers (e.g., lack of inclusive hearings and interviews), communication and information barriers (e.g., lack of Easy Read documents, braille, provision of sign language interpreters) and physical barriers (e.g., the physical inaccessibility of reception centres).

## 5.12.2 Proposed actions and solutions

Consultation participants provided a number of suggestions as to how the challenges faced by disabled people when interacting with the justice system, including the penal system, could be addressed in the new National Disability Strategy. These suggestions are listed below:

### Accessibility of the legal system

* Ensure the courts system is accessible to all, by providing reasonable accommodations and assistive technology, appointing intermediaries or court mentors, and nominating access officers;
* Strengthen legal protections and advocacy supports for disabled people; and
* Undertake initiatives to increase the accessibility of legal information and support services.

### Legal aid and the courts

* Ensure the availability of civil legal aid, including in discrimination cases; and
* Provide additional funding for advocates to support people with disabilities in court.

### Awareness of disability

* Provide training to legal professionals on disability awareness, communication with disabled people with specific communication needs, and disability rights.

### The prison system

* Include explicit recognition of people in custody with a disability in the strategy and provide targeted supports and resources for these people;
* Provide information on rights, services, and prison complaints procedures in diverse and accessible formats;
* Ensure equality of access to programmes and healthcare for people in custody with a disability;
* Support and address the reintegration challenges faced by people in custody with a disability post-release;
* Provide prison staff with continuous training on the rights and needs of people with disabilities;
* Ensure full implementation of the Public Sector Equality and Human Rights Duty across the penal system;
* Promote greater awareness and implementation of the principles of Universal Design within prison settings;
* Develop a dedicated disability strategy for the prison system designed to realise the rights and meet the needs of disabled people;
* Amend the Prison Rules 2007 to reflect UNCRPD requirements;
* Support and gather accurate and timely data on the nature and prevalence of disability among people in custody; and
* Conduct more research on prisoners with disabilities, including pre-prison and post-release experiences, young disabled people in Oberstown Children Detention Campus, and people detained in forensic psychiatric settings.

### Mental health and the criminal justice system

* Introduce legislation and other initiatives that support the effective diversion of people with severe mental health issues from the penal system (forensic psychiatric settings must not be the de facto option); and
* Ensure coherence between the new strategy and the actions contained in the Final Report of the High-Level Taskforce on the mental health and addiction challenges of people interacting with the criminal justice system.

### International protection

* Ensure disabled asylum seekers and refugees can avail of their rights to access and participate in all asylum proceedings, including the international protection determination process. Provide any necessary reasonable accommodations; and
* Ensure that Ireland’s international protection system adopts a disability-inclusive interpretation of persecution, as in many countries disabled people live in a hostile disabling environment and are at greater risk of persecution due to their disability.

# 5.13 Abuse and violence

## 5.13.1 Context and challenges

Consultation participants noted that disabled people can experience higher levels of abuse and violence, with one DPO attributing this to factors including higher levels of isolation, financial barriers to leaving abusive situations, and the exploitation of relationships of trust, including by carers. One DPO representative also stated that disabled people can feel more unsafe, particularly those with a visible disability who can face increased risk of crime, including hate crime.

Other related concerns centred on safeguarding, a lack of sex education for disabled people leading to increased vulnerability to sexual violence, and the risk of violence for some disabled people associated with using online ‘hook up’ or dating applications.

### Barriers to accessing supports

Consultation participants reported that disabled people experience barriers to accessing victim supports and justice, including communication barriers, lack of services in rural areas, and lack of awareness of available supports.

### Specific barriers experienced by disabled women and LGBTQI+ people

Some women who participated in the consultation shared personal experiences of violence and abuse, including rape and coercive control. Consultation participants voiced concern about the lack of accessible domestic violence supports for disabled women, particularly in rural areas. There was also a feeling that disabled women may be reluctant to report violence or abuse due to fears of not being believed or that their children might be taken from them. Other barriers to reporting abuse or seeking support included lack of economic independence, societal attitudes and a reluctance to use helplines due to privacy concerns. Furthermore, it was suggested that An Garda Síochána may lack understanding of domestic violence situations involving same-sex couples.

## 5.13.2 Proposed actions and solutions

Consultation participants provided a number of suggestions to address the increased risk of abuse and violence that disabled people can experience and the particular challenges they can encounter in accessing supports. These suggestions are listed below:

* Ensure accessible supports for disabled victims of abuse and violence, with a specific recommendation to ensure that disabled women have access to appropriate victim and support services, including shelters and counselling services;
* Enhance cooperation between victim support and disability organisations;
* Undertake an awareness raising campaign and provide training to relevant professionals on the risks and challenges faced by disabled women relating to violence and abuse;
* Undertake awareness raising measures to publicise supports for disabled victims of abuse and violence;
* Ensure the inclusion of LGBTQI+ people in public information campaigns on violence and abuse against disabled people;
* Include an analysis of power dynamics within anti-violence campaigns;
* Enact effective hate crime legislation;
* Progress legislation on adult safeguarding underpinned by a whole-of-government approach (beyond health and social care), in consultation with DPOs and other stakeholders, and ensure a collaborative approach to safeguarding;
* Ensure appropriate vetting of staff who work with disabled people;
* Provide sex education to disabled people. Tailor sex education programmes to include disabled bodies (this would be best delivered by those with lived experience); and
* Provide appropriate training and resources to counter violence, abuse and bullying against LGBTQI+ disabled people, including anti-homophobia training to professionals in care settings.

# 5.14 UNCRPD implementation and disability legislation

## 5.14.1 Context and challenges

Consultation participants reported concerns on the lack of effective implementation of the UNCRPD, with many referencing the ongoing delay in ratifying the Optional Protocol to the UNCRPD and divergences between disability-related legislation and UNCPRD standards.

### Lack of effective UNCRPD implementation

Consultation participants complained about a lack of effective and uneven implementation of the UNCRPD at the national level, underscoring the need to strengthen implementation and monitoring of the Convention, in consultation with DPOs and disabled people. A small number of consultation participants also shared personal stories about how the failure to fully implement the UNCRPD has negatively impacted their own lives and their children’s lives. It was noted that realising the ambition of the Convention requires comprehensive changes across legislation, policies, and programmes, in consultation with those with lived experience. One consultation participant stated:

‘Progress has been made in implementing aspects of the UNCRPD. However, more work is required to allow people with a disability to live to their full potential without discrimination. There continues to be discordance between the aspirations and policies and what is actually happening at ground level, and more action is needed.’

It was noted that there have been some challenges to securing whole-of-government cooperation on UNCRPD and disability issues, underlining the need for commitment across departments and sectors, as well as clear processes for implementing and monitoring the Convention. The importance of UNCRPD implementation at the local level, including by local authorities, and of information and awareness raising on the rights and obligations contained in the Convention were also referenced.

### Optional Protocol

DPOs and many other consultation participants regretted the ongoing delay in ratifying the Optional Protocol to the UN Convention on the Rights of Persons with Disabilities, with a significant number asserting that this instrument should be ratified immediately. Participants said:

‘We believe that that it is vital that the Government should implement the UNCRPD Optional Protocol to both expand the rights of disabled people and create a complaint mechanism which will allow individuals to hold the Government to account when appropriate. This should place the onus on the State to introduce laws and policies which are more accessible and inclusive of Autistic people and disabled people, and to consider proactively including the communities affected.’

‘[…] the Optional Protocol for the UNCRPD has to be ratified or else the rights aren’t worth the paper they are written on.’

### Disability legislation

Some consultation participants felt that existing disability legislation is not being effectively implemented and does not adhere to the UNCRPD. Some also emphasised the disconnect between the UNCRPD, disability legislation, and implementation on the ground, with ambitious policies and legislation failing to deliver positive impacts for disabled people and their families. In addition, there were calls for existing legislation to be strengthened, including in the areas of employment, education, and healthcare, and for legislation to be harmonised with the UNCRPD and made rights-based, with one consultation participant identifying terminology such as ‘strive’ and ‘as resources allow’ as problematic.

It was pointed out that some provisions of the Disability Act 2005 and the Education for Persons with Special Educational Needs Act (EPSEN) 2004 have yet to be commenced. One consultation participant stressed the importance of oversight mechanisms in ensuring compliance with disability and equality law, and cited shortcomings and difficulties in making complaints under such legislation, including through the Office of the Ombudsman.

Several consultation participants highlighted the importance of effective implementation of the Irish Sign Language Act 2017, including in education. It was also noted that strategic and specified roles are important in bringing the legislation to life and progressing the rights of Deaf people, with one consultation participant lamenting the decision to cease funding for the role of Project Officer at the Sign Language Interpreting Service. One submission drew attention to the fact that Deafblind people are not recognised in Irish law, suggesting that the next review of the 2017 Act provides an opportunity to recognise their separate identities, with the BSL (Scotland) Act 2015 cited as good practice.

There were calls for full implementation and resourcing of the Assisted Decision Making (Capacity) Act 2015 (as amended), with one consultation participant stating that legal costs pose a barrier for those wishing to become a Decision-Making Representative. Another submission highlighted the importance of consistent education and awareness raising measures for this legislation, including across health and social care settings.

There was also some support for broadening the scope of equality legislation to include intersectional discrimination and psychiatric patients, to adequately protect Deaf people, and to ensure ‘zero tolerance’ for any disability discrimination. It was further noted by a DPO representative that the Autism Innovation Strategy will not be underpinned by legislation.

Another submission highlighted concerns regarding certain provisions of the Health Act 2007, in particular that anyone who provides an emergency placement that is not a designated centre may be committing an offence. It was opined that a more appropriate arrangement for responding to those emergencies must be put in place to uphold the rights of people with disabilities who find themselves in such situations.

### Definition of disability and language

One submission noted that the definition of disability varies across Irish legislation and in many cases reflects a medical model of disability. The submission further recalled that the UN Committee on the Rights of the Child recommended in its 2023 Concluding Observations that Ireland review relevant legislation, including the Equality Acts, Disability Act and ESPEN Act, to bring them in line with a human rights-based approach to disability, particularly with regard to the definition of disability.

One consultation participant complained about the lack of accurate data on children with disabilities and their levels of need, asserting that the use of language ‘under the guise of conformity to the UNCRPD flattens the disability’ and that there should be no difficulty using the term ‘profound’.

### Alignment with other international instruments

Some submissions emphasised that the strategy should align to international and regional legislation, instruments, and policies. One submission outlined that the strategy should be a key driver of European legal frameworks and policies, including the Web Accessibility Directive, European Accessibility Act, Passenger Rights, and the European Disability Card. Another submission advocated for elements of the European Charter of Rights for Persons with Autism to be incorporated into domestic legislation.

A submission highlighted the importance of ensuring alignment between the delivery of the UN Sustainable Development Goals and the UNCRPD, with people with disabilities among those most likely to be ‘left behind’. A further submission noted that children with disabilities are rights holders under both the UN Convention on the Rights of the Child (UNCRC) and UNCRPD, with the UNCRC requiring States to undertake all appropriate legislative, administrative and other measures for the implementation of children’s rights.

## 5.14.2 Proposed actions and solutions

Consultation participants provided a number of suggestions on how to improve UNCRPD implementation and strengthen disability legislation in Ireland in the new National Disability Strategy. These suggestions are listed below:

### UNCRPD implementation

* Ratify the Optional Protocol to the UN Convention on the Rights of Persons with Disabilities;
* Ensure a whole-of-government approach to implementing the UNCRPD, with lead oversight allocated to the Department of the Taoiseach;
* Ensure effective implementation of the UNCRPD by all Government departments;
* Ensure the implementation of the UNCRPD at the local level, including through the provision of resources, the fostering of effective collaboration between local agencies, and the creation of a local taskforce;
* Implement the recommendations of the Oireachtas Joint Committee on Disability Matters Towards harmonisation of national legislation with the United Nations Convention on the Rights of Persons with Disabilities and adopt the indicators contained therein;
* Consider the policies and practices in other European countries which are more advanced in implementing the UNCRPD and replicate them;
* Incorporate the UNCRPD into domestic law;
* Undertake a review of and ensure national laws, policies, and strategies, including the new National Disability Strategy and other disability strategies, fully align with the UNCRPD (and Article 23 UNCRC);
* Increase resourcing to IHREC to monitor implementation of the UNCRPD;
* Ensure alignment between the National Disability Strategy, the delivery of the UNCRPD, and the Sustainable Development Goals;
* Ensure the UNCRPD is incorporated into the HSE’s integrated planning models; and
* Establish a nationwide agency to address disability inequality issues.

### Disability legislation

* Effectively implement existing disability legislation and strengthen laws to ensure disabled people have equal access to services;
* Introduce legislation mandating disability proofing from a human rights perspective (DPO contribution);
* Introduce legislation giving young children rights in relation to early years services;
* Fully commence the EPSEN Act 2004;
* Strengthen equality legislation, including by recognising intersectional discrimination;
* Recognise neurodiversity as a protected ground under equality legislation;
* Place the Autism Innovation Strategy on a legislative footing and introduce autism specific legislation in line with the recommendations of the 2023 Final Report of the Joint Committee on Autism;
* Reform Mental Health legislation;
* Progress legislation on adult safeguarding;
* Amend the Health Act 2007 to include provisions to respond to genuine emergencies where there is a risk to the safety of a person with disabilities in their current living arrangements and they can no longer remain living there;
* Reform existing building legislation to ensure buildings are ‘liveable’ or ‘workable’ rather than ‘visitable’;
* Introduce legislation embedding Universal Design in the employment sphere;
* Strengthen the legal requirement for service providers to engage with the National Advocacy Service (NAS);
* Progress Protection of Liberty legislation to address the gap which exists since commencement of the ADM Act; and
* Introduce a more efficient and responsive system for handling complaints under the Disability Act 2005 and Equal Status Acts, ensuring timely and appropriate responses.

# 5.15 Data and research

While not specifically asked about in this consultation, the critical need for data and research on disability was raised by a number of participants. Some of this is covered in other sections where the proposed research falls under a particular theme. This section collates the more general points made about data and research.

## 5.15.1 Context and challenges

### Collection and disaggregation of data

Most of the comments from participants, including DPO representatives, in relation to data were that more high-quality quantitative and qualitative data are required. This was considered critical to improve the lives of people with disabilities in Ireland by facilitating the:

* development of targeted and effective policies,
* development of evidence-based policies and practices that are responsive to the community's needs,
* provision of appropriate care through increased awareness of need,
* allocation of adequate economic resources,
* development of research strategies,
* planning for future service needs.

The need for data to be disaggregated by disability status was highlighted. As one organisation said:

‘There is such a dearth of disaggregated data at the moment that it makes the exercise of disability-proofing public policy akin to building a house on a giant trampoline.’

The specific needs of autistic people and how their abilities and needs can vary and evolve over time was highlighted. The Health Research Board (HRB) is responsible for collecting data on specialist disability services though the National Ability Supports System (NASS). While NASS provides an evidence base for the design and delivery of HSE-funded disability services and includes data on autistic people, some participants noted that their data are limited and do not capture all autistic children and adults in the state.

One national organisation that participated in the consultation provided examples from their own research as to how the lack of up-to-date, disaggregated data in Ireland is a key barrier to the realisation of the rights of children with disabilities. They provided an example of Tusla and the HSE, who provide and coordinate supports for children with a disability in the care of the State, being unable to come to agreement on the number of children with disabilities in State care, which has implications for the levels of support available for these children. Secondly, the lack of forward planning for school places by government explains the the problems faced by many children with special educational needs in securing an appropriate school place.

One organisation spoke of the importance of collecting quality of life indicators in order to better serve disabled people. They explained how these are often lacking in organisations that focus on finance and staffing data and in the lack of fit-for-purpose IT systems in Section 38 and 39 organisations particularly. Some organisations still have a paper-based system meaning information cannot be easily evaluated. It was reported that these organisations also lack the expertise to organise and analyse the data and cannot afford consultancy expertise to do this. According to the organisation which participated in the consultation: ‘We simply cannot implement UNCRPD if we do not know what is happening to the individuals in the sector.’

One organisation specifically raised the limited data available on people with an intellectual disability. While some data exist, the extent of changing need, unmet need, and demand for additional disability services as people with intellectual disabilities age is not fully quantified. IDS-TILDA[[24]](#footnote-25) (part funded by the HRB) findings will continue to provide evidence-based data on the health and service needs of people with intellectual disabilities as they age.

Many participants contextualised their calls for more and better data as being required under Article 31 of the UNCRPD, with a DPO participant stating that Article 31 should be an integral part of any new National Disability Strategy. Article 31 states that:

‘State parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention and to monitor its implementation.’

From a positive perspective, a consultation participant mentioned that the national Equality Data Strategy, due to be published in 2024, aims to put in place a strategic approach to improving the collection, use and dissemination of equality data in Ireland.

### Intersectional data

Many participants pointed to the need for more intersectional data, for example on the intersection between:

* mental health, disability, and the Traveller community,
* LGBTQI+ people with disability,
* children with disabilities,
* people in custody with disabilities.

With regard to mental health, one organisation noted that the Child and Adolescent Mental Health Service (CAMHS) does not collect data on younger Traveller children requiring mental health support, and as a result children are falling through the cracks. The same organisation gave an example of good practice whereby Tusla established a national working group to reach out and build engagement with Traveller groups. Tusla are also examining introduction of an ethnic identifier in data collection.

One submission highlighted how children with disabilities are subjects of rights under both the UNCRC and UNCRPD and that both conventions reference data collection.

A written submission pointed out that the Irish prison system lacks an effective screening process, meaning that many disabilities can go unrecognised and therefore unsupported. In particular, system-level data on the prevalence of physical disabilities is almost entirely absent. An increase in the prison population along with ageing issues for prisoners with disabilities will become more pressing over time. As one Irish prison health expert described: ‘Irish prisons are, in effect, emerging as congregated settings for people with psychosocial and intellectual disabilities.’

Effective data collection would allow for greater identification of the systemic barriers, inequalities and challenges encountered by people with a disability in custody, as well as the provision of targeted supports. It was noted that research and data of this kind would also greatly support the inspection and monitoring work of the Office of the Inspector of Prisons.

### Other data and research issues

One organisation complimented Irish Aid for using the OECD-DAC disability marker[[25]](#footnote-26) for tracking expenditure on disability and encouraged continued use of the marker. The same organisation talked about how they had developed people-led data approaches with DPOs that complement and provide greater depth to official statistics.[[26]](#footnote-27)

A consultation participant said that disabled people have largely been excluded from research about themselves and their lives.

## 5.15.2 Proposed actions and solutions

Consultation participants provided suggestions for how issues regarding data and research could be addressed in the new National Disability Strategy. These suggestions are listed below:

### Collection and disaggregation of data

* Highlight the importance of collecting disability data in the new National Disability Strategy as per Article 31;
* Review existing data sets to ensure they are fully used, coordinated and that gaps are identified to ensure there is disaggregated data to monitor impact and reach of policies and services;
* Fully resource the CSO to collect relevant, disaggregated, and timely data which would inform future policy development;
* Collect data regularly so that it can be compared over time, allowing changes to be assessed and trends established.
* Implement a tracking system for the allocation, use, and monitoring of resources for children in all areas of their rights, with a view to eliminating disparities and ensuring equitability, and assess how investments in all sectors serve the best interests of the child;
* Ensure disaggregated data on children with disabilities is consistently and systematically gathered, collated, and analysed by the CSO;
* Introduce a common information system across disability services;
* Enhance the NASS System;
* Conduct prevalence estimates of autism and develop an autism database and data gathering unit, for example, through expansion of the HRB’s NASS database;
* Develop more accurate descriptions of disability that include levels, e.g., profound and that use of this term should not be considered insulting;
* Formally require service providers to develop, apply and publish a set of agreed individual-based quality of life indicators associated with the services they provide; and
* Coordinate data collection on people with an intellectual disability to enable accurate forecasting and forward planning.

### Inclusive monitoring and research

* Include the lived experience of people with disability in data collection through funding for inclusive research initiatives and targeting of specific groups such as children with disabilities.

### Intersectionality

* Ensure data collection takes an intersectional approach, specifically for Travellers, LGBTQI+ people, children, and the prison population;
* Fund diverse methodologies that adopt an intersectional approach;
* Resource Traveller organisations to do research from within the Traveller community, perhaps in partnership with an outside agency; and
* Support and gather accurate and timely data on the nature and prevalence of disability among people in custody.

### Other data issues

* Use relevant data to appropriately plan for and resource services such as:
  + timely access to services and supports for children with disabilities, including school transport, medical equipment and primary care supports;
  + developing a broader knowledge base of best practice, for example, for supporting autistic people and provision of education systems;
  + forward planning for older people with an intellectual disability;
  + provision of services for people with multiple disabilities (DPO contribution).
* Fund research into:
  + current specialist supports available to parents with disabilities in Ireland and what is working in other jurisdictions;
  + the impact of home supports to prevent hospital admission, particularly for people with mental health difficulties
  + rare diseases;
  + the sustainability of informal primary care supports.
* Gather comparable, disaggregated disability data across Ireland and globally in support of measures for monitoring progress towards the attainment of the SDGs and in particular those disability-focused dimensions of the SDGs (Irish Aid and CSO to work together); and
* Further interrogate and evaluate the data inputted through the OECD-DAC disability marker to improve data quality.

# 5.16 Climate justice, situations of risk and humanitarian emergencies

## 5.16.1 Context and challenges

Several consultation participants referred to issues of climate justice for disabled people. Consultation participants referenced the negative consequences of the climate crisis for disabled people and, for example, the need for improved air quality. Consultation participants were conscious of the risks facing people with disabilities during situations of risk and humanitarian emergencies.

## 5.16.2 Actions and solutions

Consultation participants provided a number of suggestions for how the issues of climate justice and situations of risk and humanitarian emergencies could be addressed in the new National Disability Strategy. These suggestions are listed below:

* Ensure that any climate adaptation and mitigation, and disaster preparedness approaches include the views of people with disabilities and their representative organisations at a local level;
* Engage with DPOs from the outset in relation to local and national plans to decarbonise Irish society (DPO contribution);
* Ensure that consultation opportunities on climate solutions that affect disabled people are available in hybrid or online options and that physical spaces are accessible (DPO contribution);
* Ensure that any public investment to address the climate crisis is fully inclusive of the needs of disabled people (DPO contribution); and
* Address the needs of people with disabilities in the context of climate change within the National Disability Strategy. Leave no one behind and reach the furthest behind first, as per The UN Agenda for 2030.

# 5.17 International co-operation

## 5.17.1 Context and challenges

A consultation participant requested that Ireland’s approach to disability inclusion carry over to the State’s overseas development policy and aid budget. They requested that the National Disability Strategy make explicit reference to overseas development assistance and Ireland’s policies on international development, reflecting work carried out by Irish charities to end the cycle of disability and poverty within the Global South.

## 5.17.2 Actions and solutions

They proposed a number of actions for the NDS:

* Demonstrate Ireland’s commitment to disability inclusion in its overseas development work and engagement on global issues within the National Disability Strategy e.g., Global Disability Summit, Inclusive Humanitarian Charter;
* Implement the recommendations of the Oireachtas Joint Committee on Disability Matters Towards harmonisation of national legislation with the United Nations Convention on the Rights of Persons with Disabilities with respect to Article 11 and Article 32 of the Convention;
* Adopt a ‘twin track’ approach to overseas development policy and funding, with mainstreaming and targeted support to address the needs of specific communities in relation to disability inclusion;
* Create flexible funding systems which can adapt in the wake of major geopolitical events; and
* Provide require targeted support to address the specific needs of people with disabilities in Ireland’s international co-operation, including a dedicated strategy/policy on disability inclusion and earmarked financial commitments through Ireland’s overseas aid budget.

1. Caring for people with disabilities

A number of consultation participants emphasised the importance of acknowledging families and care in the new National Disability Strategy, with one submission highlighting the lack of such acknowledgement as a weakness of the previous National Disability Inclusion Strategy (2017-2022). One submission recognised that associating disability with care can be contentious, given the history of paternalism towards disabled people from the medical, social, and family systems within Ireland. However, they noted it cannot be denied that while some disabled people do not need care from family members, there are others who do require this care, ranging from a little help with some aspects of life to significant help with all aspects of daily living.

Caregiving is a reality for many families in Ireland. Throughout the consultation, caring was discussed from a number of perspectives by participants - by parents of disabled children and adults, carers of disabled parents, and carers of disabled spouses and other family members. It was suggested in the consultation that not recognising this caregiving in a National Disability Strategy is excluding the disabled people for whom it is relevant:

‘Acknowledging and valuing the contributions of caregivers is crucial for the success of any strategy aiming to improve the lives of disabled individuals.’

# 6.1 Context and challenges

There was a clear message from the consultation that carers feel unsupported by the State. Carers noted that they feel invisible and that their value is not acknowledged, particularly when they are not paid for their caring role or are paid a small amount due to means testing and taxing of financial support. ‘Exhaustion’, ‘stress’ and ‘burnout’ were used a number of times when discussing carers, underscoring the potential negative impact of caring on physical and mental health. Despite these impacts, consultation participants referred to not having access to any supports themselves:

‘Please respect the levels of exhaustion of parents/guardians of disabled children - we need better levels of support to continue to give high quality care for our amazing children. In many situations families like ours have no medical/educational/developmental experience prior to having our disabled child, and suddenly we are thrust into a role where we’re expected to be medical, educational, developmental experts and practitioners - all on a shoe-string and with little sleep. Respect the dignity of our family - don’t make us beg for intervention & support.’

A number of consultation participants discussed the challenges of balancing employment and caring. One referred to the importance of parental leave entitlements to their family’s quality of life. However, they also noted that they cannot move jobs in the future due to the rule that generally you must have been working for your employer for a year before you are entitled to parental leave. This has an impact on their career progression.

A number of carers referred to the challenge of having to fight for what their loved one needs. With that, it was noted that if the problems accessing health and social care services and supports, housing for disabled people, and supports for independent living (as outlined in Chapter 5) were addressed, the lives of family carers would improve. A consultation participant referred to the need for actual hands-on interventions from services, rather than the expectation that parents should learn how to do the intervention, as this just adds to their burden:

‘Hands on [service] This is what children and exhausted parents need - not ANOTHER role that we simply do not have the mental or physical capacity to take on. As a family, we are already exhausted from caring for our child’s medical, nutritional, cognitive etc. etc. etc. needs. We need hands-on help, not ‘empowerment’/justification for non-intervention’.’

## Respite services

Respite was cited as an essential part of the carer system in Ireland, but one of the most common issues raised about caring was the lack of respite available nationwide. The particular impact of this on full-time carers of those with highly complex needs was highlighted.

## Planning for future care

Another issue raised frequently by carers in this consultation was the lack of any mechanism to enable them to plan for their children’s futures, particularly in the event they themselves become ill, get too old to care for their child, or die. It was clear this caused a lot of stress to carers and to disabled people themselves. During the consultation, worries about the future were also linked to a lack of confidence that services were adequate to support their loved one. When carers talked about the future, they used terms like ‘terrified’, ‘petrified’, ‘very worried’ and ‘frightening’. One consultation participant stated:

‘We need to plan for the future. Our children are going to become adults- adults are going to need help. I just can’t think about the future, I just can’t because I think I’d give up on life.’

Issues related to inheritance and care were raised on several occasions, with people worrying about how an inheritance might impact on their loved one’s access to supports and ultimately leave them less well-off and less supported. One participant would like to know whether it would be feasible to give their house to the HSE for the care of their children.

## The financial impact of caring for someone with a disability

Throughout the consultation, many participants referred to the financial challenges of caring for someone with a disability in Ireland. A recurring message from consultation participants was that the current provision of financial supports for carers of disabled people is inadequate. This was particularly with regard to the increase in the cost of living and as families often take on responsibility for paying the extra costs for the person with a disability (e.g., paying for medication, services, supports, aids and appliances, travel - see Chapter 5). A number of participants expressed frustration with the fact that the initial COVID-19 Pandemic Unemployment Payment was higher than Carer’s Allowance.

Consultation participants also referred to ways in which carers may lose income, for example by having to reduce their work hours, leave their employment, or take unpaid leave to care for their disabled loved one. If they are caring for someone who has acquired a disability, there is a possibility that this income has now been lost from the household. The financial pressures on caring families were apparent from these consultation participants.

A number of people felt the current system of benefits and entitlements is flawed: some people who need to provide care have no choice but to work because they do not qualify for Carer’s Allowance, while other people have to give up work to care, but do not qualify for Carer’s Allowance because of a partner’s income, so their loss of income to the household is not addressed. It was noted that for those individuals who do not qualify, they are essentially not getting paid for what they are doing, which was considered unfair. The means testing of Carer’s Allowance was mentioned by a number of people as being ‘unfair’, and one person described means testing care support as ‘inhumane’. One consultation participant explained:

‘Never once has the government acknowledged the contribution of the time I have given to advocate, reassure, comfort or care for these parents, because my family earns over the means test.’

The same problems around dependency as discussed in Chapter 5 also applies for carers who are means tested. One person noted:

‘As I am not recognized as a carer who qualifies for Carers Benefit I have to beg my husband for money if I need it for something! It’s just degrading. This is a disgrace in a country where I was forced to give up work to become a carer who can’t identify as a carer because I wasted so many years educating myself and being a higher rate tax payer.’

One consultation participant gave an example of leaving a domestic violence situation, getting maintenance for themselves and their child, but not being eligible for Carer’s Allowance because of this maintenance payment.

Several participants raised the issue of Carer’s Allowance being taxed, with one noting: ‘Carers are providing a vital service for the Government and should not be financially penalised.’

The introduction of PRSI stamps for long term carers was appreciated; however, a participant asked: ‘But what about helping us until the day we qualify for the old age pension?’

Carers also reported that applying for entitlements was challenging and invasive.

## Domiciliary Care Allowance (DCA)

One person expressed concern with the rule that if a child is in hospital for more than 26 weeks in a 12-month period, their DCA is stopped. However, all the other extra costs of disability do not stop during this time, and costs like travel, parking, and food increase, while income is likely impacted by having to take time off work. It was noted that this criterion seems unnecessarily punitive at what is already a vulnerable and challenging time.

## Issues affecting the Travelling Community

Consultation participants from the Travelling Community discussed there being a gender imbalance in the burden of care in Ireland, with it being noted that women were more likely to be carers. It was felt that this burden is even greater for Traveller women, especially for older Traveller women, given Traveller women are more overrepresented in the home than in the settled community and as there are higher levels of illness and disability in the Traveller community.

# 6.2 Proposed actions and solutions

Consultation participants provided many suggestions for how challenges for carers of people with disabilities could be addressed in the new National Disability Strategy. These suggestions included acknowledging the importance of the caring role, improving respite provision, enabling planning for future care, improving the financial situation of carers, and providing support for carers.

## Recognition of care

* Include families, carers, and supporters within the language of the strategy. This is to reflect the reality of significant numbers of disabled people in Ireland today who do require such care and to acknowledge the importance of the caring role.

## Respite services

* Improve provision of respite for disabled children and adults. One submission requested that disabled children have automatic access to regular, reliable, and safe home-based respite; and
* Introduce a legal entitlement to respite for carers.

## Planning for future care

* Develop a mechanism to plan for future care. This process needs to involve discussions with people with disabilities and carers and joined-up thinking to plan clear pathways to address future needs;
* Provide information to carers about the impact of inheritances on the supports for people with disabilities;
* Plan transitions appropriately – for example, work with carers to support people into independent or supported living in a timely way;
* Plan for care in urgent or emergency situations, such as a carer going into hospital,
  + In cases where a carer is in need or struggling, it was suggested that every GP is the country could be directed to an online system to flag to the relevant resource that a carer needs support; and
* Ensure that advocacy for the disabled person is included in future plans.

## Benefits and entitlements for caring

* Reform the current system of benefits and entitlements for carers;
* Increase the level of financial support to carers (e.g., Carer’s Allowance) to enable a decent standard of living and to recognise the value of their role;
* Remove means testing for financial supports or means test the carer, not the household;
* Make Carer’s Allowance non-taxable;
* Make Fuel Allowance available for carers;
* Allow parents to keep DCA no matter how long their child is in hospital;
* Remove the requirement for diagnosis (due to current issue with Assessment of Need) in the application for DCA;
* Expand the ‘incapacitated’ child tax credit to include parents/carers of children with any disability/diagnosis of chronic illness;
  + Replace ‘incapacitated’ terminology and rename as living with Disability/ Illness tax benefit;
* Provide automatic non-means-tested financial support, e.g., Carers Allowance, Domiciliary Care Allowance etc., for parents/guardians/carers of children with life-limiting conditions;
* Provide a standardised, liveable income for all parents of children with disabilities and carers;
* Introduce a separate carer cost of disability payment;
* Provide tax credits for carers that are employed;
* Provide respite grants for everyone that cares for a vulnerable person, so they are taking breaks every year that are not means tested;
* Make application forms for entitlements easier and less invasive; and
* Ensure Deciding Officers respect and listen to carers.

## Supports for carers

* Improve the information provided to parents and carers on disability following diagnosis;
* Provide targeted and tailored family support packages for parents and carers of those with disabilities to support resilience and wellbeing;
* Provide a service for carers which includes counselling and advocacy training;
* Provide accommodation for carers in adult hospitals for disabled adults who have high support needs;
* Provide speech and language training for the parents of children with autism;
* Introduce supports for carers in employment:
* Introduce reasonable accommodations in the workplace for parents/carers of those with disabilities;
* Change the 12-month rule on entitlement to parental leave to ensure parents of children with disabilities have the opportunity to move within the workforce; and
* Provide paid carer’s leave for attending appointments with the person they care for.

## Gender and the provision of care

* Address the impact of gender imbalance in the provision of care on women in the strategy; and
* Include a consideration of intersectionality – for example, the likelihood that a higher proportion of female Travellers are carers than settled females.

1. Conclusion

The purpose of this report was to summarise the breadth of the contributions made by a wide range of disability stakeholders from November 2023 to February 2024 to inform the new National Disability Strategy (NDS). The consultation process was underpinned by principles of meaningful engagement with disabled people and other stakeholders. Consultation participants shared diverse views, expertise and lived experiences regarding many challenges and barriers that people with disabilities face participating in society in Ireland. Importantly, participants also recommended and proposed many actions and solutions to address these challenges.

The contribution of DPOs was specifically highlighted throughout this report. In general, there was a strong call from DPOs for more advocacy, voice, and representation. DPO representatives stressed the importance of accepting, centralising, and prioritising the views of DPOs in decision-making processes. They stressed the importance of their meaningful involvement in the development and monitoring of the NDS, but so too in strategies and action plans more widely. DPOs described how they were currently constrained by limited funding and resourcing and called for supports to build their capacity to fully undertake their role as per Article 4.3 of the UNCRPD.[[27]](#footnote-28) Without adequate resourcing, they believed the ‘status quo’ of making decisions about disabled people, without disabled people, will remain intact.

There was general alignment between the issues most commonly rated as important to disabled people’s quality of life by survey respondents and the frequency with which these issues were raised across other consultation activities (which included non-disabled as well as disabled participants). For example, the areas of health and social care services and supports, financial independence and security, transport, accessibility, independent living and housing were among the most frequently raised across consultation activities and also among the most likely to be rated as important in the survey. The issues of culture, leisure, recreation, and sport were more prominent in the survey responses than they were in discussions with adults with disabilities but featured quite strongly in discussions with children and young people. The issue of meaningful relationships was very rarely raised in consultation discussions but was rated as important by more than half of survey respondents. This suggests these topics warrant more prominence in future consultations.

The survey findings on others’ awareness and treatment of respondents with disabilities are in line with the challenges reported from DPOs and others in discussion groups and in written and video submissions about people’s experiences of discrimination and the poor disability awareness and negative attitudes of others. A very clear message from this consultation is that there is a need for impactful, widespread awareness raising campaigns on disability, as well as targeted disability competence training, in particular for public service staff, employers, and health and social care staff.

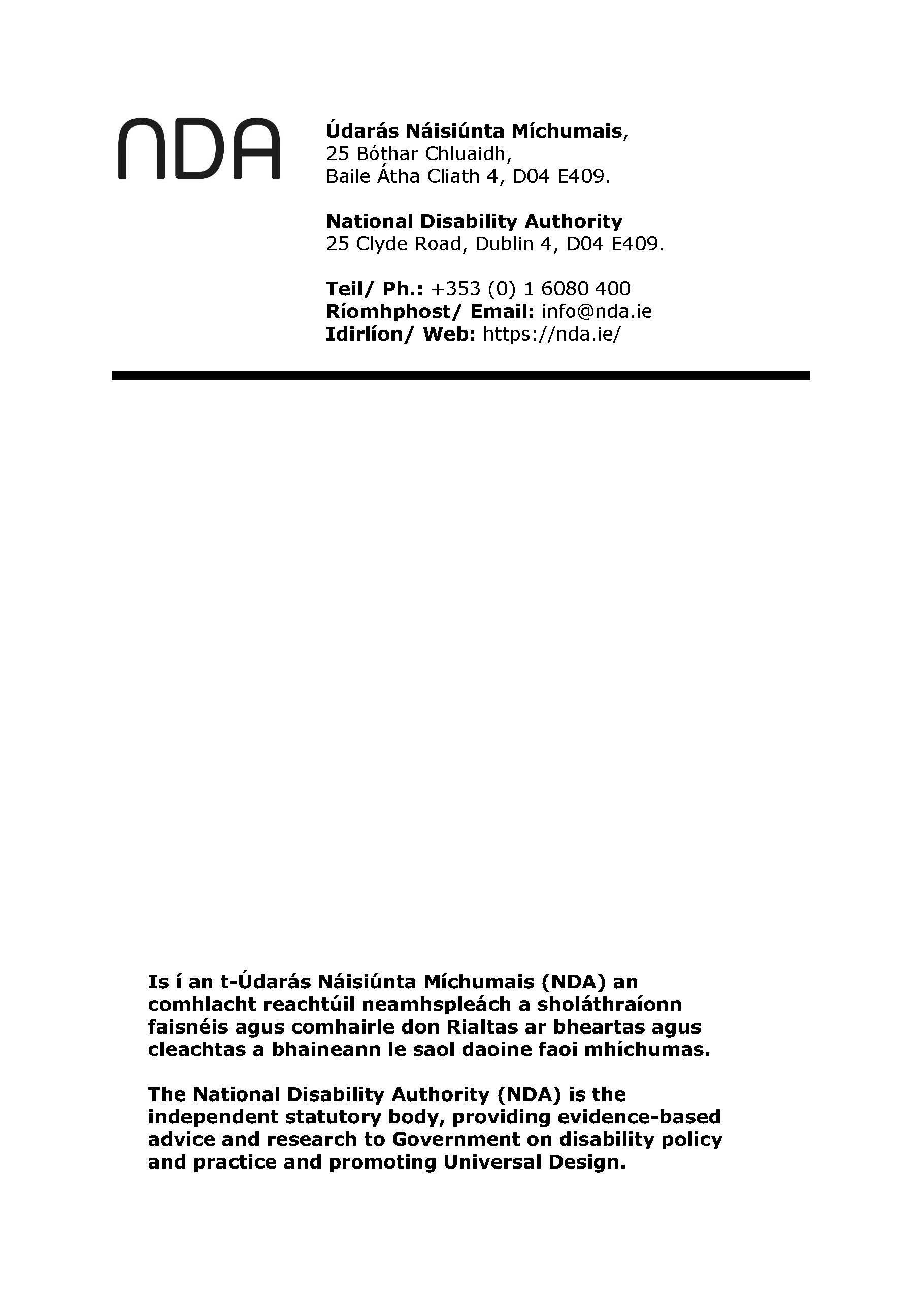
Throughout the course of the consultation, the National Disability Authority regularly shared emerging findings with the Department of Children, Equality, Disability, Integration and Youth to help inform the ongoing development, approach, and content of the new NDS. It will not be possible for all contributions and proposed actions to be included in the strategy. The intention of the NDS is to have high level impactful objectives delivered through five main pillars. Each pillar will in turn develop an action plan which will be informed by this report. However, all the content in this report provides an extremely valuable record of the concerns and suggestions of Disabled Persons’ Organisations, disabled people, their families, service providers, civil society organisations, advocacy bodies and carers.

While the primary purpose of this document is for use in developing the NDS, we encourage stakeholders to use this report in other ways, for example, to inform reporting ahead of Ireland’s first examination under the UNCRPD, including to produce shadow reports by civil society organisations. The extensive feedback provided could be used to shape the national disability research agenda and government policies, through the identification of new research directions and policy gaps. The information could also be used as a resource to inform targeted advocacy campaigns as well as disability equality training and awareness raising initiatives. When considering the recommendations in this report, we encourage people to be inclusive of children, young people and adults with disabilities. Finally, as the experience of disability cuts across all other rights-based agendas, the intersectional lived experience in this report can be drawn upon to inform upcoming national equality policies in areas such as LGBTQI+, migrants and Traveller rights.

We look forward to the new NDS, informed by this report, that will promote the human rights of all disabled people in Ireland.

# Appendix A – Organisations who submitted written or video submissions

* Acquired Brain Injury Ireland
* AHEAD
* AsIAm
* Brothers of Charity Services Ireland
* Care Alliance Ireland
* Chime
* Christian Blind Mission (CBM) Ireland
* Citizens Information Board
* Coalition 2030
* Conradh na Gaeilge
* Cork Chamber of Commerce
* Council of Irish Sign Language Interpreters
* Cystic Fibrosis Ireland
* DARA
* Debra Ireland
* Department of the Environment, Climate and Communications (SDG Unit)
* Disability Federation of Ireland
* Dyslexia Association of Ireland
* Dyspraxia/DCD Ireland
* Enable Ireland
* Erris Youth Disability Network (Mayo North East SICAP)
* Extern Ireland
* Families for Reform of CAMHS
* Finglas Children’s Disability Network Team
* Fionnathan Productions
* Gaeloideachas
* Health Information and Quality Authority (HIQA)
* Health Research Board (HRB)
* HSE Cregg Services
* Inclusion Ireland
* Inclusive Education Alliance
* Irish Heart Foundation
* Irish Nurses and Midwives Organisation
* Irish Penal Reform Trust
* Irish Society for Autism
* Irish Wheelchair Association
* Kerry Travellers Health and Development Project
* Longford Community Resources CLG
* Munster Technological University (UNESCO Chair)
* National Advocacy Service
* National Disability Authority
* Neurological Alliance Ireland
* Office of the Inspector of Prisons
* Ombudsman for Children
* Open Doors Initiative
* Outhouse LGBTQ+ Centre
* Polio Survivors Ireland
* Reach Deaf Services
* Rehab Group
* Shine
* South Tipperary Disability Groups Forum (HSE Gold Star Project)
* Sunbeam House Services
* Technological University Dublin (Business School)
* The Arts Council of Ireland
* The Association of Occupational Therapists of Ireland
* The Multiple Sclerosis Society of Ireland
* The National Federation of Voluntary Service Providers Supporting People with Intellectual Disability
* Trinity Centre for People with Intellectual Disabilities
* Vision Sports Ireland
* Voice of Vision Impairment



1. Please note that in addition to this national consultation there was ongoing direct consultations between DCEDIY and DPOs that are not captured in this report. [↑](#footnote-ref-2)
2. Individuals with disabilities may belong to multiple different racial, ethnic, gender, or socioeconomic backgrounds. These intersecting identities can influence their experiences and the types of challenges and barriers they encounter. [↑](#footnote-ref-3)
3. ‘Nothing About Us Without Us’ is a slogan used by DPOs and disabled peoples’ movements to illustrate the principle of the active involvement of persons with disabilities in the planning of strategies and policies that affect their lives. [↑](#footnote-ref-4)
4. We acknowledge that some DPOs may prefer the term Disabled Persons’ Representative Organisation (DPRO). [↑](#footnote-ref-5)
5. Article 4(3) of the UNCRPD states: ‘In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.’ [↑](#footnote-ref-6)
6. UN Committee on the Rights of Persons with Disabilities (2018) General Comment No.7 on the participation of persons with disabilities, including children with disabilities, through their representative organizations, in the implementation and monitoring of the Convention, available at the following link: <https://www.ohchr.org/en/treaty-bodies/crpd/general-comments> [↑](#footnote-ref-7)
7. NDA (2024) Supplementary Resources to Inform the Development of a New National Disability Strategy. [www.nda.ie](http://www.nda.ie) [↑](#footnote-ref-8)
8. Please see the full ACE report ‘Report on a Consultation with Seldom Heard Disabled People on the new National Disability Strategy’ at www.gov.ie [↑](#footnote-ref-9)
9. Please see the full ACE report ‘Report on a Consultation with Children and Young People on the new National Disability Strategy’ at www.gov.ie [↑](#footnote-ref-10)
10. In cases where percentages do not add up to 100%, this is due to people not answering the question, in some cases noting that they preferred not to answer the question. [↑](#footnote-ref-11)
11. The Census 2022 questions on long-lasting conditions or difficulties were used in the survey as per guidance by the National Statistics Board, with some amendments based on guidance from DPOs. However, several consultation participants expressed frustration that there was no option to tick neurodivergence or autism and that ‘blindness’ was not an option, only ‘visual impairment’. [↑](#footnote-ref-12)
12. These percentages are of the total number of people who responded to each item. The percentage of missing values for these items ranged from 0% (housing) to 6% (sports or activities). [↑](#footnote-ref-13)
13. The Disability Stakeholders Group was a voluntary group of representatives from Disabled Persons’ Organisations, disability NGOs and service provider organisations, as well as individuals with lived experience of disability, whose function was to monitor the implementation of the National Disability Inclusion Strategy 2017-2022. [↑](#footnote-ref-14)
14. For more information see the International Network on the Disability Creation Process (iNDCP) <https://ripph.qc.ca/en/hdm-dcp-model/the-model> [↑](#footnote-ref-15)
15. Ableism is a set of beliefs or practices that favours ‘able-bodied’ people in social institutions. Ableism devalues and discriminates against disabled people. [↑](#footnote-ref-16)
16. CREATE is a digital and assistive technology fund from the HSE. [↑](#footnote-ref-17)
17. It is not national policy for attendees to pay for day services, although they may pay for their chosen activities in the community. [↑](#footnote-ref-18)
18. Ostomy surgery of the bowel is when the large or small intestine is connected to the skin on the outside of the abdomen. After this the contents of the digestive system leave the body through an ostomy pouch. [↑](#footnote-ref-19)
19. [Access to Work: get support if you have a disability or health condition: What Access to Work is - GOV.UK (www.gov.uk)](https://www.gov.uk/access-to-work) [↑](#footnote-ref-20)
20. The Green Paper was withdrawn in April 2024 [↑](#footnote-ref-21)
21. Minimum disposable income required to avoid poverty in 2023 calculated by Social Justice Ireland using CSO SILC and earning data [↑](#footnote-ref-22)
22. [Just a minute of patience | JAM Card | Autism | Hidden disability | Northern Ireland](https://www.jamcard.org/) [↑](#footnote-ref-23)
23. Motability is a scheme in the UK that support people with disabilities to achieve greater independence, by giving you access to affordable, worry-free mobility such as wheelchair accessible vehicles, adapted cars, scooters, and powered wheelchairs. Recipients in receipt of a mobility allowance are eligible and their mobility allowance is paid directly to Motability. [Motability Scheme | Lease a car, WAV, scooter or wheelchair](https://www.motability.co.uk/) [↑](#footnote-ref-24)
24. IDS-TILDA is a longitudinal study researching ageing in Ireland among people with an intellectual disability aged 40 and over. [↑](#footnote-ref-25)
25. In 2018, the Organisation for Economic Cooperation and Development’s Development Assistance Committee (OECD-DAC) introduced the ‘disability policy marker’ – a tool to monitor how far Official Development Assistance (ODA) aims to be inclusive of persons with disabilities. The marker allows the DAC members to track their own projects in international cooperation and humanitarian action and see on a scale from 0 to 2 how much they target persons with disabilities. [↑](#footnote-ref-26)
26. Citizen-generated data refers to the data that individuals or their respective organizations produce to directly monitor, demand, or drive change on issues that profoundly impact them. This type of data is generated through various means, such as surveys, texts, phone calls, emails, reports, storytelling, and social media. It can take the form of quantitative or qualitative information, structured or unstructured, and can either be open or closed. [Citizen-Generated Data and Persons with Disabilities (cbm-global.org)](https://cbm-global.org/wp-content/uploads/2024/02/Report-Case-studies-of-data-generated-by-OPDs-FINAL.pdf) [↑](#footnote-ref-27)
27. Article 4(3) of the UNCRPD states: ‘In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.’ [↑](#footnote-ref-28)