An Phríomh-Oifig Staidrimh
Central Statistics Office

Irish Disability Survey

Pre-Pilot Report 2026

Content

List of Acronyms

CSO	Central Statistics Office
DCDE	Department of Children, Disability and Equality
DPO	Disabled Persons' Organisation
ESCoP	European Statistics Code of Practice
HSE	Health Service Executive
ICD-11	International Classification of Diseases 11th Revision
ICF	International Classification of Functioning, Disability and Health
IDS	Irish Disability Survey
ISL	Irish Sign Language
ISO	International Organization for Standardization
ISSCoP	Irish Statistical System Code of Practice
NDA	National Disability Authority
NDS	National Disability Survey
rATA	rapid Assistive Technology Assessment tool
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
WG	Washington Group
WHO	World Health Organization

Statement on Language

Language is very important to all of us. Using appropriate language can guide us in how we support the rights of disabled people. It is also important to acknowledge that language preferences can change and evolve. It is important to ask a disabled person what their language preference is, as this may vary across the disabled community.

We use “identity first” language in this report. We describe someone as a “disabled person” rather than saying “a person with a disability”. The term “disabled people” is recognised by many within the disability rights movement in Ireland as aligning with the human rights approach to disability. This was the preference expressed in engagement with Disabled Persons Organisations. The wording acknowledges the fact that people are disabled by various barriers that may hinder their full and effective participation in society on an equal basis with others.

We also recognise that others may prefer the term “people or persons with disabilities”. This term reflects an understanding that they are first and foremost human beings entitled to human rights. We also acknowledge that some people do not identify with either term.

Executive Summary

Under Article 31 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), Ireland is obliged to collect appropriate information, including statistical and research data, to develop and implement policies in line with the Convention. In 2006, a National Disability Survey (NDS) was conducted by the Central Statistics Office (CSO), the results of which were used to plan services, develop policies, and for further research. The 2006 survey is now considered dated, and its usefulness for current policy development is limited. The Department of Children, Disability and Equality (DCDE) have proposed running a new national survey on disability following the 2027 Census of Population, as set out in the National Human Rights Strategy for Disabled People 2025-2030. The new survey will be collected by CSO as the Irish Disability Survey (IDS) in 2028.

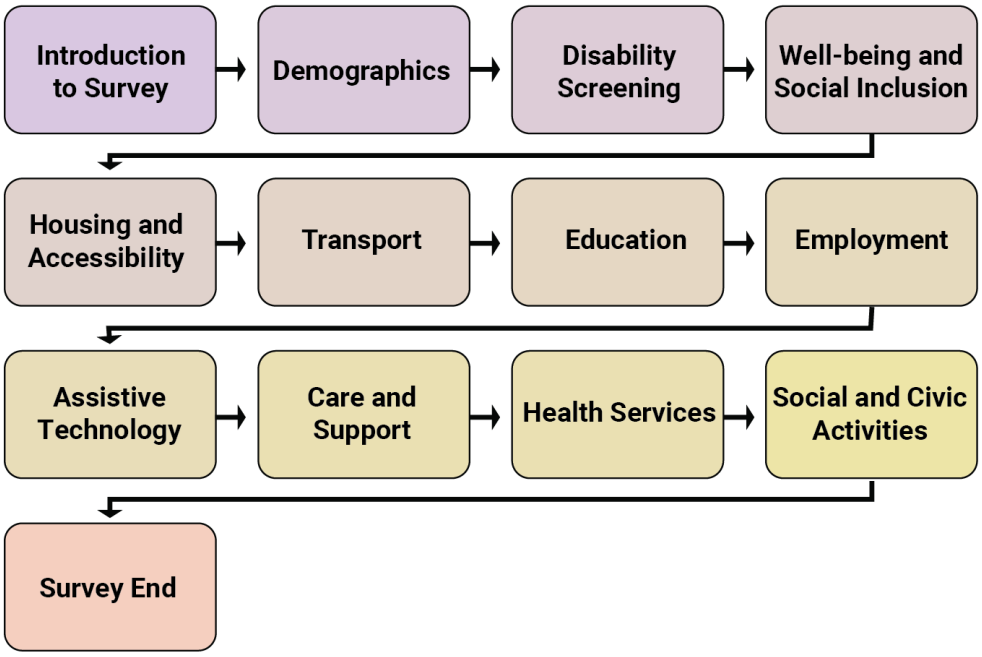
Throughout 2025, a series of cross-government, public and subject matter consultations took place, to produce a prioritised list of content requirements for the IDS. The IDS Steering Group, led by DCDE and with representatives across government, academia, the disability sector, and people with lived experience, received this list in October 2025. At that time, it was accepted it would not be possible to include all proposed content in the IDS 2026 pilot.

In this report the CSO outlines what content will be taken into the next phase of development, IDS questionnaire design, as well as what content is out of scope. Survey questions are being developed and refined throughout 2026, using CSO expertise, consultation with international counterparts, and DPO engagement.

This report presents the survey content on a module-by-module basis. Modules are a way of organising the survey; each module focuses on a particular topic, and questions are grouped into the appropriate modules. Image 1 shows the proposed flow of survey modules for the 2026 IDS pilot. The survey will begin with an introduction section and followed by eleven themed modules on demographic information, disability screening, well-being and social inclusion, housing and accessibility, transport, education, employment, assistive technology, care and

support, health services, and social and civic activities. The IDS will close with a survey end section.

Image 1: flow of the IDS pilot questionnaire modules



Throughout this report, detail on what is in and out of scope across the survey modules will be given.

The disability screening module will play a pivotal role in the questionnaire design. It will establish how respondents flow though the survey, and more importantly how disability is defined. Developing a screening module is challenging, as there is little to no broad agreement, nationally or internationally, on a definition of what is meant by ‘disabled’. The 2026 IDS pilot will use a new screening method, to better align to national and international best practice, and stakeholder recommendations.

The final section of this report outlines the ongoing secondary data review. The integration of primary and secondary data is a key mechanism used by the CSO to reduce burden on respondents. This review will continue through the questionnaire design phase, informing the structure of the final survey questionnaire.

The content recommendations outlined in this report were approved by DCDE and the wider IDS Steering Group in January 2026. The recommendations presented in

this report will be subject to further refinement as the design phase is progressed by the CSO throughout 2026. This means that some of the content outlined in this report could potentially change or be excluded before the pilot survey goes into the field. The pilot will commence by the end of 2026 and into the first quarter of 2027.

Introduction

The purpose of this report is to inform data users and other stakeholders in the disability sector about what content will be included in the Irish Disability Survey (IDS) 2026 pilot, particularly the new and revised topics, and the reasoning behind any changes from the 2006 National Disability Survey.

Following a consultation phase led by The Department of Children, Disability and Equality (DCDE), the Central Statistics Office (CSO) have taken received data requirements, to create a survey questionnaire design for the 2026 IDS pilot. The CSO is Ireland's national statistical institute, who's role is to provide independent statistics about our society, economy, and environment, which are freely available to everyone and support evidence-informed decision making.

For Official Statistics to be of value, they must be trusted. The statistics produced by the CSO are regulated by the principles set out in the European Statistics Code of Practice (ESCoP) and in the Irish Statistical System Code of Practice (ISSCoP). The purpose of ESCoP and ISSCoP is to ensure the quality and credibility of the data underpinning official statistics.

During the IDS consultations, stakeholders highlighted a lack of up-to-date data and in some cases an absence of data in the overall area of disability. Stakeholders also flagged data quality issues in relation to the 2006 National Disability Survey (NDS): some of the 2006 survey content was outdated or in need of refinement, therefore not meeting some important data needs. In response, and in line with our codes of practice for data quality, the CSO recommend some significant changes to what we ask and how we ask it in the IDS. Given the time gap between the 2006 survey, the quality dimensions of relevance, accuracy, and current national and international consistency were prioritised, over providing a comparative time series.

The Irish Disability Survey

Under Article 31 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), Ireland is obliged to collect information, including statistical and research data, to develop and implement policies in line with the Convention. Ireland is also required to monitor the implementation of the Convention and to identify and address the barriers faced by disabled people in exercising their rights.

In 2006, a National Disability Survey was carried out by the CSO with a sample of people indicating that they had a disability in the Census of Population 2006. The results were used to plan services, to develop policies, and for further research on a range of topics.

At nearly 20 years since its collection, the information from the 2006 survey is now considered dated, and its usefulness for current policy development is limited. The DCDE have proposed that a new disability survey be conducted following the 2027 Census of Population, as set out in the National Human Rights Strategy for Disabled People 2025-2030. The new survey will be collected as Irish Disability Survey (IDS) in 2028 (pilot in 2026) and will replace the National Disability Survey (2006). A change in name is to reflect the break in time series due to changes in the disability landscape. See Appendix 1 for a full list of relevant framework and strategies informing the development of the Irish Disability Survey.

Consultation Process and Selection of Content

In 2024 DCDE (formally DCEDIY) convened and chaired a survey Steering Group. The IDS Steering Group consists of representatives from the National Disability Authority (NDA), Government Departments, the Disabled Persons' Organisation (DPO) Network, the Disability Federation of Ireland and Academia (see Appendix 2 for a full list of Steering Group members). The Steering Group agreed that first steps were to run a series of consultations. The Steering Group asked the NDA to conduct a public consultation, focusing on DPOs and academia. DCDE ran a cross-government consultation. The focus of these consultations was to establish if there was a need for a new national survey on disability and what this might look like.

These consultations focused on exploring potential content for a new disability survey. Methodological considerations, such as sample size and selection, questionnaire design, or mode of data collection, did not fall under the remit of these consultations.

Fourteen departments and two agencies contributed to the cross-government consultation and as part of the public consultations, feedback was received from 28 organisations, and 15 individuals representing themselves. There was overwhelming support for running a national disability survey.

The Steering Group identified five core themes emerging from both sets of consultations. Subsequently, the Steering Group agreed to establish five subject matter subgroups. The objective of these subgroups was to discuss and prioritise content for inclusion in the next national survey on disability. The five subgroups were:

1. Employment
2. Transport
3. Assistive Technology
4. General Topics
5. Neurodevelopmental conditions

Sub-group membership was established by DCDE, with representatives from various government departments, academia, sectorial bodies and DPOs (see Appendix 3 for a full list of subgroup members). Each sub-group was co-chaired by CSO and a subject matter expert from DCDE, Department of Social Protection, Department of Transport, Health Service Executive (HSE), and the NDA.

The sub-groups returned a prioritised list of all data requirements to the Steering Group in September 2025. At this time, it was agreed it would not be possible to include all content proposals in the IDS 2026 pilot. Therefore, it was necessary for the Steering Group to further prioritise this list, to support the next phase; the questionnaire development by the CSO.

Prioritisation of Content and Next Steps

The next section of this report outlines the content that the Steering Group have recommended be taken forward into the pilot questionnaire design phase.

The rationale for any topics considered out of scope for inclusion in the pilot will be discussed, and may fall under the following reasons:

- The topic can be accessed from an administrative data source
- The data is already available in another survey or data source, which is classified by disability status
- The subgroup is too small to get statistically meaningful data from a sample survey
- The topic would be better explored through qualitative research
- The topic would require too many sub-questions to accurately measure, and would add greatly to response burden, or crowd out other topics
- No validated measure of the topic available, in national or international studies
- The topic largely duplicates an included topic
- The topic was ranked lower by subgroup members, or has lower policy relevance than topics recommended for inclusion

It is important to note, that the wording presented throughout the report is used to illustrate the topics proposed for collection. It does not reflect the final wording that will be used in the survey questionnaire. Question wording is being refined throughout 2026 and ahead of the pilot, using the expertise of our questionnaire designers, consultation with international counterparts, as well as engagement with the DPO Network.

Engagement with the DPO Network will primarily take the form of cognitive interviewing. Cognitive interviewing is a method used to develop high-quality surveys, by evaluating how respondents interpret and answer questions. It involves

conducting one-on-one interviews, often using "think-aloud" or verbal probing techniques, to identify question problems with comprehension, memory retrieval, judgment, or response mapping. This iterative process ensures questions are valid, reliable, and unbiased. Cognitive interviewing is one element of the CSO's planned DPO engagement over the next phase of development.

Lastly, the survey content presented in this report will be subject to further refinement as the electronic questionnaire is programmed and tested. This means that some of the content outlined in this report could potentially change or be excluded before the pilot survey goes into the field. The pilot will commence by the end of 2026 and into the first quarter of 2027.

Pilot Content

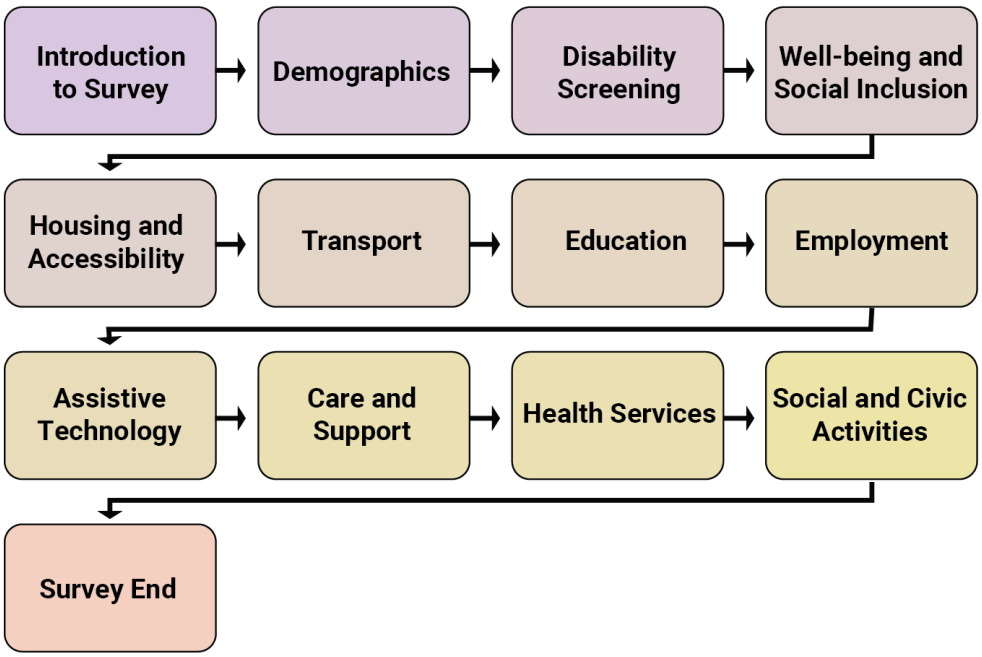
This report details the contents of the 2026 IDS pilot on a module-by-module basis. Modules are a way of organising the survey; each module focuses on a particular topic, and questions are grouped into the appropriate modules. A proposed flow for the IDS modules is presented in Image 1. This flow is subject to change, following testing during the questionnaire design phase.

It is important to note that the flow of questions, or the questions themselves, may vary depending on the respondent. For example, factors like age (child vs adult questionnaire), setting (private households vs communal establishments), and who is answering the survey (direct vs proxy response) will influence the questionnaire design and be refined throughout the next phase of development.

Only individuals who meet a certain threshold based on the answers given in the screening module will be filtered into the subsequent modules on well-being, housing, transport, and so on.

Image 1 shows the proposed flow of survey modules for the 2026 IDS pilot. The survey will begin with an introduction section and followed by eleven themed modules on demographic information, disability screening, well-being and social inclusion, housing and accessibility, transport, education, employment, assistive technology, care and support, health services, and social and civic activities. The IDS will close with a survey end section.

Image 1: flow of the IDS pilot questionnaire modules



Demographics Module

The introduction to the survey will collect information on who is answering the survey to determine if the response is direct, supported or proxy.

Following the introduction and within the demographics module, it is necessary to ask or confirm a range of demographic data in the questionnaire, regardless of using a Census of Population sample frame. This is to facilitate question filtering throughout the survey modules. Demographic information collected from the respondent may include sex, gender, age, sexual orientation, ethnicity, employment status, and marital status.

Other demographic topics will be added from the Census of Population sample frame and will not be asked directly of the respondent in the questionnaire. These may include citizenship, housing status, household composition (one person, cohabiting, and so on), parental status, and deprivation index.

Disability Screening Module

Overview

To identify disabled people in a population survey, questionnaire designers use a **screening module**. The screening module is made up of **suitable questions and a threshold**. The threshold is based on responses given to the questions by survey respondents. **Together, the questions and the threshold, set the criteria for counting a person as disabled in the survey**.

Developing a disability screening module is challenging because there is little or no broad agreement nationally or internationally on a definition of what is meant by 'disabled,' nor is there a standardised method for identifying the disabled population in surveys. Changes in the understanding of disability and approaches to collecting data about disabled people since the survey was last run in 2006 mean the screening method used previously is no longer fit for purpose. The 2026 IDS pilot will use a new screening method.

The development of the 2026 IDS pilot screening module will begin with screening methods recommended by the UN Washington Group on Disability Statistics (WG). The Washington Group Extended Set on Functioning provided the basis for the adult questions and the Washington Group and UNICEF Child Functioning Module for the child set.

Considerations will be given to the question sets used in the national surveys; Irish Health Survey (aligned to the regulatory European Health Interview Survey), which utilises the Budapest Initiative questions. Additionally, we will consider best practice set by comparative international disability surveys, notably Stats New Zealand's 'Household Disability Survey'; Statistics Canada's 'Canadian Disability Survey'; and the Australian Statistical Bureau's 'Survey on Disability, Ageing and Carers'.

Additions and amendments will be required to the WG questions, based on requirements set by the Steering Group and Sub-groups. Other amendments may come as a result of findings from focus groups or cognitive interviewing, international comparators, survey length constraints, and to better meet stakeholder data needs and the survey's objectives.

The disability concept being measured in the IDS is functional and is underpinned by the International Classification of Functioning, Disability and Health (ICF). There are different ways of conceptualising disability. Historically, the medical model was the most prominent way of thinking about disability. The medical model explains disability by measuring diagnostic criteria or impairments. The medical model is increasingly being replaced by the social model of disability. While the social model acknowledges that an individual has an impairment, it also states that disability is caused by their environment and societal barriers, rather than the impairment itself. In other words, a person is disabled by society, not by their body or abilities.

The 2026 IDS pilot will use the ICF as the framework for measuring disability. The ICF (also known as a social-relational model) explains disability as an interaction between a person's capabilities (limitation in functioning) and environmental barriers that may limit their participation in society (see Appendix 1 for further details).

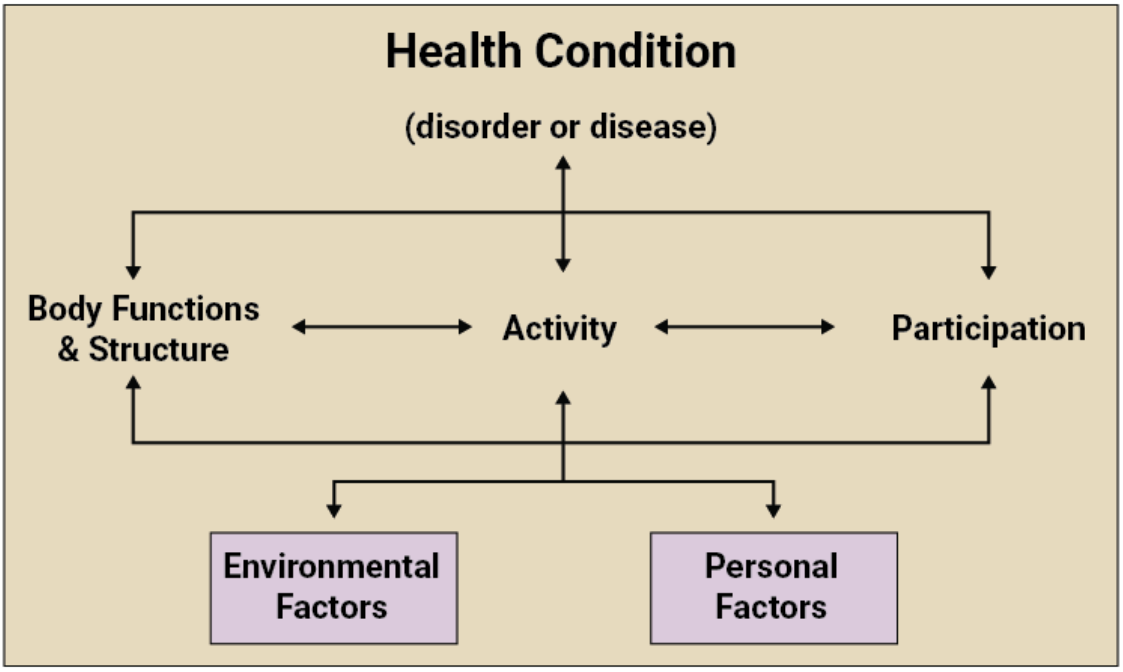
Image 2 shows a visualisation of the International Classification of Functioning, Disability and Health (ICF) framework. The ICF illustrates disability as the interaction between a person's health conditions and contextual factors.

The image shows how the core ICF components are interconnected. The core ICF components are:

- **Health Condition:** The underlying disorder or disease.
- **Body Functions & Structures:** Physiological functions and anatomical parts. Impairments are difficulties in these areas.
- **Activities & Participation:** What a person does and how they engage in life situations. Here difficulties in activities and participation are called limitations and restrictions.
- **Environmental & Personal Factors:** The physical, social, and attitudinal environment (e.g., societal barriers) and personal traits (e.g., age) that influence functioning.

Under the ICF, disability involves dysfunctioning at one or more of these same levels: impairments, activity limitations and participation restrictions.

Image 2: the ICF model of disability



To uncover the disabling social environment, there is a need for an underlying measure of disability prevalence. To do this it is important to follow the ICF framework, which is consistent with the social model where the disability is caused by barriers in society rather than the person's impairment. The IDS screening questions will focus on functioning in relation to basic, universal activities, such as difficulties in walking, rather than on diagnosis (medical model). Those screened into the survey will then be asked under different modules about barriers in the environment or society that may restrict their participation (social model).

Additional benefits of this approach for the Irish Disability Survey will be the availability of detailed information on functional, as well as environmental challenges. This is key to inform transport policy, design of the built environment, the design of public services and communications, supports for independent living, among other public policies. A different range of solutions may be needed to design environments and services that accommodate people with varied needs. For example, how many wheelchair spaces to provide on trains.

IDS Disability Indicators

The screening questions will ask about the **level of difficulty** respondents have when completing functional activities like seeing, hearing, or walking. Asking about specific functioning leaves less room for response ambiguity; questions that are easily and consistently understood by respondents are vital for ensuring the measurement of disability is reliable and valid for national statistics.

In addition to capturing the level of functional difficulty as a disability indicator (which is in line with NDS 2006), there was strong support from stakeholders to capture **level of severity** as a second indicator. A measure of severity was not included in the NDS in 2006, and again there is little or no broad agreement nationally or internationally on a definition of what is meant by "disability severity". Statistics Canada have developed a severity score in their disability survey, by combining **level of functional difficulty** with **frequency of impact**. This approach will be considered during the IDS questionnaire development phase.

The ICF model, which focuses on functional difficulties, is inclusive of people who have significant difficulty with basic functioning, but don't consider themselves disabled or as having a disability. For example, people with debilitating health problems, chronic conditions or difficulties caused by ageing might not describe themselves as disabled but will often meet a functional threshold. Although they might not identify themselves as disabled, it is important for these people to be counted in national statistics because they too need access to funding, supports, and services.

There will be two sets of screening questions: one for children and one for adults. Respondents aged 15 and older will complete the adult version of the survey and 14 and younger will be issued the child version of the survey. These cut-offs are subject to review over the development phase. The child survey will be completed by a parent or guardian. During the questionnaire design phase, considerations will be made on how best to capture the voice of the child.

Screening for Adults (respondents aged 15 years and over)

The two disability indicators, **level of functional difficulty** and **frequency of impact** will be combined to produce a **severity score.** A defined **threshold** for this severity score will need to be established during the questionnaire design phase, and ahead of the IDS pilot. This threshold will be used to identify the population at risk of disability, and to filter respondents into the other survey modules. For example, The Washington Group recommends a threshold of 'a lot of difficulty' or 'cannot do at all', when using the WG question sets.

The following functional difficulties have been proposed for inclusion in the adult screening module:

- Seeing (even if wearing glasses or contact lenses)
- Hearing (even when using a hearing device)
- Mobility; walking 100 meters, walking 500 meters, and walking up or down stairs
- Dexterity; picking up small objects, or opening or closing containers
- Flexibility; lifting a two-litre bottle of milk from waist to eye level, bending, or reaching
- Personal care such as showering and dressing themselves
- Communication; understanding or being understood
- Concentrating
- Remembering
- Learning new things
- Emotional, psychosocial or mental health difficulties; including feeling anxious, depressed, or another mental health difficulty
- Pain
- Fatigue
- Breathing
- Intellectual functioning or condition

In addition to the functional difficulties listed above, several items were proposed to better capture difficulties experienced by neurodivergent people. These items were

not included in the 2006 survey and will be designed and tested during the IDS pilot development phase.

- Socialising or mixing with others
- Sensory overload
- Becoming distressed or overwhelmed or reaching a meltdown
- Accepting or managing changes to routine
- Challenging behaviours, such as hitting, screaming, and so on

Respondents will be able to report multiple difficulties, and the sequence of questions will be generally consistent across all assessed functional difficulties. For example, questions for seeing difficulties may reflect the following:

1. Do you wear glasses or contact lenses? Yes, No
2. Do you have difficulty seeing, even when wearing your glasses or contact lenses? No difficulty, some difficulty, a lot of difficulty, cannot do at all
3. How often does this difficulty seeing limit your daily activities? Never, rarely, sometimes, often, always
4. In the last 12 months, did this difficulty seeing…? Get better, get worse, stay about the same. *(to capture progressive disability)*
5. At what age did you begin to have this difficulty seeing? *(to capture disability onset)*

This pattern of questions will be repeated for each functional difficulty. The combination of questions on level of functional difficulty and frequency of impact will facilitate a severity score being established. We will review and utilise methodology established by Statistics Canada, which derives a severity score based on functional difficulty and the frequency of impact on daily activities. Establishing a level of severity would not be possible by asking level of functional difficulty alone, as was done in NDS 2006.

Screening for Children (respondents aged 14 years or younger)

The following child disability screening sets were informed by Stats New Zealand and the WG Child Functioning Module. Parents or guardians of respondents below the age of 14, will be invited to participate on behalf of the child. As with adults, the screening questions for children focus on the respondent's ability to carry out

specified activities or their functional difficulties. Functioning tends to improve with age, so the child questionnaire will have three variations of the screening questions to suit the child's expected stage of development based on their age. There is no limit on how many functional difficulties a child can screen in on.

Screening for children younger than 2 years old

The following functional difficulties have been proposed for inclusion in the child screening module, for children younger than two:

- Seeing (even if wearing glasses or contact lenses)
- Hearing (even when using a hearing device)
- Flexibility; moving any part of their body, for example waving their arms, kicking their legs, or turning their head
- Playing
- Developmental delay

Screening for children aged 2–4 years old

The following functional difficulties have been proposed for inclusion in the child screening module, for children aged 2 to 4 years old:

- seeing (even if wearing glasses or contact lenses)
- hearing (even when using a hearing device)
- Communicating; understanding or being understood by their caregiver or parent
- Mobility; walking on level ground (without using support)
- Dexterity; using their hands to pick up small objects
- Flexibility; bending down or reaching in any direction
- Learning new things
- Playing
- Development delay
- Controlling behaviours; kick, bite, or hit a lot more than other children of the same age

Screening for children 5-14 years old

Children aged 5-14 years old will be considered disabled if they have a lot of difficulty with, or cannot do, any of the following:

- Seeing (even if wearing glasses or contact lenses)
- Hearing (even when using a hearing device)
- Communicating; being understood when speaking to people they live with and who they don't live with
- Mobility; walking 100 meters, and 500 meters, on level ground (without using support)
- Dexterity; using their hands to pick up small objects
- Flexibility; bending down and reaching in any direction
- Personal care such as dressing or feeding themselves
- Learning new things
- Concentrating
- Remembering
- Accepting change to their routine
- Controlling their behaviour
- Making friends
- Intellectual disability
- Feel very worried, nervous, or anxious everyday (as observed by their parent)
- Feel very sad or depressed everyday (as observed by their parent)

Neurodevelopmental Status

During stakeholder consultation, information on diagnosed Autism and diagnosed ADHD was identified as a data requirement. A decision on whether diagnosis will be incorporated into the disability threshold (based primarily on level of functional difficulty) will be reviewed during the design phase. If undiagnosed, self-identified Autism and ADHD will also be collected.

Other Topics

Other topics that will be captured within the screening module but will not be factored into the threshold to identify the population at risk of disability include:

- If the respondent communicates through Irish Sign Language (ISL), and if so, whether ISL is the respondents first or preferred language
- Age of onset; for each reported functional difficulty respondents will be asked when this difficulty started. During the stakeholder consultation, there was interest in learning whether differences exist between those who were disabled since birth or at a young age, versus people who acquired their impairments later in life
- Progressive difficulty, for example whether the functional difficulty got better, worse, or stayed the same over the last two years
- Multiple impairments will be derived in processing, post data collection, based on screening in on multiple difficulties

Any remaining topics suggested by stakeholders during the consultation phase, but considered out of scope for the pilot, are detailed in the next section.

Topics not Included

There was a lot of interest to capture detail on various functional difficulties and behavioural differences. A balance is needed here to ensure the screening module doesn't become overly burdensome. Considerations were made towards which topics align to international comparators, and topics that were too specific to provide meaningful data. Internal sensory difficulties, for example difficulty with balance and movement, body position and force, or internal body signals, such as hunger signals, were deprioritised based on stakeholder recommendations.

During the consultation process there was some interest to collect information on written or oral communication difficulties, and sleep difficulties. It was agreed that these topics largely overlap or are related to some in-scope-topics detailed above. Detail on difficulties with specific daily tasks beyond personal care, and difficulties adapting to new environments were deprioritised from the screening module but some information on these topics will be collected elsewhere in the survey.

The consultation revealed some interest in learning more about disability status and how people identify with certain labels or conditions. There were suggestions to capture detail on disability status categorised as acquired, progressive, intermittent, idiopathic, or congenital. There was also a suggestion to collect specific detail on long-term illnesses, health problems or conditions, as classified under the ICD-11 framework. There was a suggestion to ask respondents if they identify as 'neurodivergent' and if formally diagnosed, whether the neurodivergent diagnosis was received through a public or private process. There was some interest in medication usage, but this ranked lower than other topics retained for inclusion.

Well-being and Social Inclusion Module

The topics included in the well-being and social inclusion module, and the modules to follow, will be asked of the participants who meet the disability threshold. Certain topics will not be included for proxy responders or within the child questionnaire. This is because well-being measures are often subjective, meaning they need to be answered by the person themselves.

The well-being and social inclusion module will include topics on:

- Mental and physical health
- Quality of life or general well-being
- Overall life satisfaction
- Loneliness
- Social inclusion
- Safety within the home and within the community
- Support systems
- Overall satisfaction with personal relationships
- Impact of various peoples' attitudes and whether they support or hinder the participant
- Experiences of discrimination, and on what grounds
- Where this discrimination was experienced
- The ability to make autonomous or independent choices about daily life
- Whether the respondent identifies as a disabled person

- Experience of bullying at school (child questionnaire only)

Topics not Included

There was considerable interest in the well-being and social inclusion module, and many topics were deprioritised to ensure the module wasn't overly burdensome for participants and to reduce overlapping topics. There were requests to collect information on resilience, feeling independent, self-esteem, and feelings of personal fulfilment. These topics were deprioritised as they ranked lower than topics retained for inclusion.

It was agreed that other topics, such as income adequacy and additional detail on experiences of discrimination (such as the frequency of occurrence), would be better explored in other CSO surveys such as the Survey on Income and Living Conditions or the Equality and Discrimination Survey.

There were requests for the survey to collect more information on autonomy, the ability to make life changes if desired, and the one-good-adult concept. While we recognise that these would provide valuable information, such topics would require a significant number of questions and would add greatly to response burden. There was also interest for the survey to collect information on the impact of adverse events such as climate change, storms, and COVID-19. We recognise that these are interesting areas of research, however it may be better suited to qualitative research, as the sample sizes would be too small for a national survey.

There was some interest in collecting information on parental experiences, such as experiences as a disabled parent, attitudes of others towards parental ability, and detail on the parent-child relationship. It was agreed this topic would require a significant number of questions to fully explore and may be better suited to its own piece of research or separate module in the future.

Unlike the 2006 survey, the survey will not be including questions on the level of stamina, smoking status, or general feelings of trust in other people. Removing topics will make room for other new content.

Housing and Accessibility Module

The housing and accessibility module includes topics on specific housing adaptations that have been completed in the participants' home. If adaptations are required, participants will be asked about the barriers to access. Participants will also be asked about the general suitability of their home, in terms of accessibility.

This module will also capture information on accessibility outside of the home. Participants will be asked about accessibility issues outside the home, and location of these issues, and more generally about accessibility issues within their community.

Additional housing-related information will be added from other available sources, such as the Census of Population. Administrative data relevant to this module may include housing tenure, social housing status, dwelling type, the number of rooms, and whether the participant lives alone.

Distance to amenities was discussed in several consultations. For example, proximity to supermarkets, medical centres, libraries, green spaces, public transport, hospitality and retail venues were suggested as amenities of interest. This data will fall under a wider "access to key services" project, which is being conducted by other surveys in the CSO.

Topics not Included

Participants residing in communal establishments will be included in the pilot sample with participants from private households, and disaggregated by other factors such as sex, age and disability type. There was interest in data dissemination by residence type, but due to the anticipated number of respondents living in communal establishments being small relative to those living in private households, this will not be possible.

This survey won't include questions on specific accessibility needs on a room-by-room basis, nor will it ask when adaptations were completed. Accessibility issues within specific locations, such as school, will also not be asked within this module, but may appear elsewhere in the survey.

There was some interest in collecting information on difficulties beyond the physical environment, such as difficulties with noise or weather and questions relating to future adaption needs, home heating ability or barrier to adequately heating homes, and the desire to live independently. These topics were deprioritised as they ranked lower than topics retained for inclusion and to ensure the housing module isn't overly burdensome.

Transport Module

The transport module focuses on four modes of transport: public transport, private transport, other transport services, and active travel.

Public Transport

Respondents will be asked if they use any public transport services, including public bus (city, intercity, rural), taxi or hackney, light rail (DART, Luas), trains (commuter, intercity), or door-to-door (such as TFI-Anseo).

Respondents will then be asked a series of questions relating to public transport, including frequency of use of each public transport option, overall satisfaction with each service they use, if they have a travel pass and whether they transfer between services. If they are unsatisfied with a mode of public transport, they will be asked what the reason is.

For those who do not report using any of the above public transport options they will be asked if they would like to use the service. If so, they will be asked what barriers are preventing them from using the service across a range of themes, including accessibility, information and service issues.

Private Transport

Respondents will be asked if they use private transport as a driver or as a passenger. Respondents will then be asked a series of questions relating to private transport, including, if they have access to the vehicle when required, and if they avail of a parking permit.

For those who do not report using private transport, they will be asked if they would like to use this mode of transport. If so, they will be asked what barriers are preventing them from using the private transport.

Other Transport Services

Respondents will be asked a series of questions relating to use of any other transport services. This relates to non-public services, for example those provided by disability services, elderly centres, private bus companies, and voluntary organisations.

For those who do not report using other transport, they will be asked if they would like to use this mode of transport. If so, they will be asked what barriers are preventing them from using other transport.

Active Travel

The Department of Transport defines Active Travel as 'travelling with a purpose, using your own energy'. For example, walking, cycling, wheeling, and scooting, to make journeys to work, school or the shops are all considered forms of Active Travel. Active Travel is a new transport category added since the 2006 survey.

Respondents will be asked if they use any form of active travel when making day-to-day journeys, including cycling, walking or running, wheeling, or scooting.

For those who do not report using active travel, they will be asked if they would like to use this mode of transport. If so, they are asked what barriers prevent them from using the active travel.

Topics not Included

There were requests for us to collect more information on purpose of journey, detail on successes or benefits of transport use, awareness of transport schemes, and whether the participant uses public transport independently or requires a companion. These topics were ranked lower than topics retained for inclusion.

For private transport uses, there was interest to collect data on whether the vehicle was electric, the vehicle year, whether the vehicle was modified, and who the main

driver of the private vehicle was. We recognise that this would be valuable information, but it would require a significant number of questions, and we have decided to prioritise other topics for which there was a greater demand by data users.

Unlike the 2006 survey, we will not be including a question on the level of difficulty experienced when using each transport mode. Removing questions will make room for other new content, such as active travel.

Stakeholders recommended that certain information be included for some, but not all transport types. This was to ensure the transport module was not overly burdensome to participants. Frequency of use was deprioritised for all transport types except public.

Education Module

Stakeholder feedback highlighted the need to collect information from both children and adults, as well as participation in both formal and informal education. Informal education might include life-long learning and work-related training. Information on the type of informal training will be collected. Participation will be restricted to a certain time period to ensure relevance and to minimise issues with recall.

For respondents who are not currently in education or have not participated in education recently, they will be asked if they would like to attend and what barriers might prevent their participation. In the 2006 survey, respondents were asked directly if they had left education sooner than desired due to their disability, and this topic will be retained but might be refined during the design phase.

Information on barriers within education, required supports or unmet needs for supports, and school type (mainstream or specialised) will also be collected. There was an interest to measure school belonging or connectedness for children, and this concept will be explored during the design phase.

There was interest to collect information on transition points for young people. There were also requests for information on a desire to attend third level education after

secondary school and what barriers are discouraging young people from wanting to attend further education.

Highest level of education will be added from the Census of Population.

Administrative Data

Some administrative data will be added to supplement the education module. School absences over a threshold of 20 days, and the reason for the reported absence will be added via administrative sources.

Topics not Included

There was interest in collecting data on barriers to lifelong learning and enabling factors to further education. These topics were considered to overlap with the in-scope topics outlined above. There was also a suggestion to collect specific reasons why a respondent left education early, whether the respondent requires additional supports outside of school, the level of education when functional difficulties or disability started, and reason for wanting to participate in education. These topics ranked lower than topics retained and ultimately were deprioritised to ensure the module isn't overly burdensome.

Other topics which would lend themselves better to other research methods include topics on invisible disabilities and the related challenges or barriers within education. Data on awareness or update of social inclusion programmes such as Social Inclusion and Community Activation Programme (SICAP) or Community Services Programmes (CSP) were deprioritised as the numbers for these would be too small to get meaningful data from.

Employment Module

The employment module will include a range of questions for both persons in employment, as well as those not working. Principle Economic Status, collected in the demographic module, will be used to filter individuals into the relevant employment questions.

For persons in employment, they will be asked about their employment status to capture self-employment, their hours worked and whether they would like to work more or less hours, general job satisfaction, and barriers within their employment.

For persons outside of the labour market, they will be asked if they worked previously, the reason for leaving and when they left. Respondents will also be asked if the situation was right would they like to work, what barriers are preventing them from working and if they would like full- or part-time employment.

There was an interest to collect information on future goals. This may relate to promotion, retirement or for those outside the labour market, getting a job. This concept will be considered in the design phase. There was also an interest to collect information on transition points for younger people and barriers preventing them transitioning from school into employment.

Administrative Data

Additional data will be linked to the employment module for respondents in employment, including income, detail on industry and occupation, and whether the respondent works in the public or private sector.

Topics not Included

There were requests for us to collect more information on topics which largely duplicated included topics. For example, there was interest in collecting information on enabling factors within work, and benefits of self-employment. For respondents in employment, there was also suggestions to collect detail on previous promotions, or promotion discrimination, detail on whether the respondent thought their qualification matched their role, and whether the respondent had disclosed their disability to their employer. Ultimately it was decided these topics would be better captured by other research methods.

The stakeholder consultations revealed some interest in learning more about people outside of the labour market. There was interest in capturing detail on why they would like to work, enabling factors that would support people transitioning into employment, whether the respondent had recently applied for roles, and if so, what applications supports they had used. There was interest understanding if a fear of

disclosure preventing respondents from applying for roles. There was also some interest in collecting data on alternative activities such as job scheme, rehabilitated training, therapeutic craft, social enterprise, and training. Due to the length of the survey and to ensure respondents aren't being overly burdened these topics were deprioritised due to ranking lower than topics retained for inclusion.

Detail on work related training will be captured more generally in the education module. There was some interest in examining old age transitions, including the experience transitioning from disability benefits to old age pension. However, it was agreed this would be better explored using qualitative methods. Lastly, information on specific career supports accessed in school was deprioritised due to small subgroup size.

Assistive Technology Module

The comparable module in the 2006 survey only asked about "aids". The 2026 pilot survey will greatly increase the scope by asking about products or technology. This is not just a change in terminology, it is also indicative of the progress in technology, and how widespread assistive technologies have become in the past decade.

Use of health services, such as physiotherapist or occupational therapist, was included in the comparative module in 2006. This information will be collected within its own health services module for the 2026 pilot. This module may collect information across grouped functional difficulties. For example, the category lists may be grouped in line with the WHO rATA groupings, vision, hearing, mobility, communication, learning, remembering, personal-care, and other difficulties, to minimise overlap in products and technology.

The assistive technology module will capture information on:

1. The use of assistive products or technology, based on the functional difficulty reported
2. Unmet need: whether there is assistive products or technology needed, based on the functional difficulty reported
3. Barriers which prevent respondents from accessing assistive products and technology

Where multiple products or technology are used, the survey will ask respondents to identify their three most important products. Respondents will then be asked for further information on this shorter list, to better understand service provision needs.

- Information on procedural services used to access assistive products or technology, including product selection, product set-up, training, follow-up care, and any other services
- Satisfaction with the assistive product or technology
- Pay source

Topics not Included

For people who use assistive products or technology, it was suggested the survey collect information on access to, rather than use of, assistive products, barriers of use (rather than barriers to access), the benefits of use, and facilitators of both access to and use of assistive products. It was agreed there was considerable overlap between these topics and while nuanced, the survey would be better serviced by including other topics.

Due to the length of the survey, other topics that were deprioritised due to lower support from stakeholders included duration of use of the product, capturing the specific product names under the International Organisation for Standardisation (ISO) classifications, whether the products were customised or off the shelf, the sources used to gather information on the products, and who owned the product (for example the HSE or the respondent).

While some procedural information will be collected in the survey, other topics have been excluded to ensure the module is not overly burdensome. This included information on who helped the respondent select their assistive product, the level of satisfaction with the selection process, and who provided the service to set up the product. Information on the length of time taken to receive the product after selection, time taken for follow-up care, and time taken for any repairs will also not be asked.

Within the procedural topics, there was interest to collect information on the pay source for training and follow-up care. These topics were deprioritised to make space for collecting information on the pay source of the product itself. Specific information on cost, including cost of training, cost of repairs and cost of purchase will not be included in the 2026 pilot. There was lower support for cost related information, and we believe this information would be better captured elsewhere. There was some interest in gathering information on co-funding schemes. However, as this is not a common method of funding within the Irish context it was deprioritised to make space for other topics.

During the consultation phase, there was interest to capture the use of assistive products across a range of activities, including education, employment, in social settings, in transport, in care settings, to support independent living, or more generally in daily life. Rather than asking specific questions on these topics, analysis of this assistive technology module and the other survey modules should provide insights. For example, correlations between the use of, or barriers to access of, assistive products and participation in employment.

Care and Support Module

Within this module respondents will be asked about difficulties carrying out specific daily tasks, such as preparing a meal, managing finances, or doing housework. Information on how many respondents receive help or support with everyday activities will also be collected. Of those who receive help or support, stakeholders requested information on who provides this support, with a particular interest to separate out personal assistants and carers. How frequently the support is accessed and whether this is sufficient, and detail on whether the support is paid for by the family, will also be captured. If the respondent is not receiving support, they are asked if they would like to receive help and the barriers preventing them from accessing support.

Information on care services such as day care services, meal centres, residential care, and respite services, was collected in the NDS 2006 and will be collected again.

Information on whether the respondent provides care or support to others will be added to the module via the Census of Population.

Topics not Included

The consultation revealed a lot of interest in learning more about the pay source for care or support services, and the cost of such care. These topics were deprioritised to ensure the module isn't overly burdensome for respondents. The frequency of access of care services and whether this frequency was sufficient were also deprioritised due to lower support.

Health Services Module

Respondents will be asked whether they have accessed any health services in the last 12 months from a list of specific services. There were many requests to expand the list of health professionals and services. The category list will be finalised during design phase, and may include, for example, family doctor or GP, occupational therapist, speech and language therapist. There is an important balance needed here to ensure the category lists aren't overly long and negatively impact the quality of data collected.

The challenge of this module is that any follow-on questions would be repeated for each service access, resulting in an overly long module. To minimise this burden, respondents will be asked to identify the three most important services which support their daily life. Follow up questions will only be asked on these services, similarly to the approach taken within the assistive technology module. To get a better understanding of service provision, respondents will be asked for additional detail on:

- How frequently they accessed the service
- If they would like to access the service more frequently
- Satisfaction with the service

To measure unmet need, respondents will be asked what services they would like to access and what barriers prevent them from accessing those services.

Administrative Data

Administrative data on health-related benefits, such as medical card access or other state benefits will be included to supplement this module and to better understand service provision and need.

Topics not Included

The consultation revealed some interest in learning more about diagnostic services, particularly around access, barriers to access and whether the service is public or private. However, this topic was deprioritised due to lower support compared to topics retained. Similarly, there was some interest in the length of time to access but it was agreed this would be better captured more generally as a barrier to access.

Social and Civic Activities Module

Participants will be asked a range of questions about their participation in social and leisure activities. In 2006 this module was divided into a social participation module and a sport and exercise module. During the consultation phase, stakeholders recommended that these modules be combined and to reduce the number of questions related to sport. It was agreed that data on sport is well captured elsewhere, such as the Irish Health Survey.

Within this module respondents will be asked if they participated in various social or leisure activities such as community events, in physical activity, or online. Information on level of satisfaction with their social life and any barriers preventing any desired social participation will be collected.

There was an interest in collecting information on political participation. This includes whether the respondent voted in the last election, and if not, were there any barriers that prevented the respondent from voting.

Topics not Included

Initially there was a lot of interest in collecting a wide variety of information on sport and exercise. However, following much discussion, stakeholders recommended this be deprioritised as this topic is well captured elsewhere. Topics within this area included participation in various physical activity or sport, barriers to participation in

sport, the frequency of participation in sport, whether the respondent is a member of a disability specific sports team, the level of intensity of the physical activity they engage in, the length of time a respondent participates in each physical activity, the setting the sport takes place (for example, mainstream, community facility, or specialised setting), and whether the activity is team or individual based.

Volunteering was another topic where there was a lot of interest, but ultimately it was agreed that this topic was well captured elsewhere, for example, in the Census of Population. Participation in volunteering, the frequency of volunteering and the setting where the respondent volunteers were all suggested as topics of interest.

Unlike the 2006 survey, the IDS pilot will not include a question on the level of difficulty experienced when participating in various social activities. Nor will respondents be asked about how frequently they engage in various social or leisure activities. Information on whether the participant travelled for a holiday will also not be collected. These questions have been removed to make room for new topics.

There were requests to collect data on a number of other topics, but these were subsequently ranked as having lower support when compared to topics that will be included. These include data on the night-time economy, the number of friends or who the respondent socialises with, and general hobbies. There was interest in collecting information on disabled parent's participation in school related events. There was also interest in social media participation and specific online activity. While some information on online participation will be collected, it will not go into detail on specific usage or participation.

While some information will be collected on political participation, there was an interest to collect additional data on this topic and on participation in activism, both in disability groups and other forms of activism. It was agreed the subgroups would be too small to get meaningful data from these cohorts and these topics would be better explored by other research methods.

Qualitative Survey Data

There was a recommendation from the Steering Group to include one open-ended question at the end of the survey, to collect qualitative data. For example, the

qualitative approach may be to ask participants to share any other information about their life or disability that they think is relevant. This will be explored during the development phase, to determine if and how this might look in the IDS.

Administrative Data

Administrative data is information that is collected by other government departments and agencies for their own purposes, which is then used by CSO for statistical purposes.

In the preparation of this report, the CSO have commenced a review of any disability related administrative data, which may support the survey development. This involves reviewing all administrative sources currently held by the CSO. The CSO are also considering any other sources which may not be held currently by our Administrative Data Centre, but which we may need to acquire from our government partners.

Topics which fall under the admin data review include employment, education, transport, communal establishments, health, housing, benefits and schemes including Department of Social Protection payments. For example, income data will be added post collection from the PAYE Real-Time Data source received from Revenue.

This administrative data review will continue throughout the next phase of development, to ensure administrative data is well integrated into the design and build of the IDS 2026 pilot.

Appendix 1: Disability Frameworks and Strategies

The purpose of Appendix 1 is to outline the relevant frameworks and strategies which will inform the development of the Irish Disability Survey (IDS).

United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)

Ireland ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2018. The following articles are particularly relevant to the IDS.

Article 1 of the UNCRPD states that

"*Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others*".

Article 31 states that

"*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*".

The National Human Rights Strategy for Disabled People 2025-2030

In line with the UNCRPD, Ireland has moved away from a medical model of disability towards a social model. This is reflected in the National Human Rights Strategy for Disabled People 2025-2030 which is Ireland's plan to advance the realisation of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). The Strategy is centred around five key pillars identified as priorities by people with disabilities and their representative organisations:

- Inclusive learning and education
- Employment
- Independent Living and Active Participation in Society
- Wellbeing and Health
- Transport and Mobility

Under the Strategy, there is a commitment to strengthen our capacity for disability research and data to support evidence informed policymaking. One of the key vehicles for this commitment is through the completion of an Irish Disability Survey, post Census 2027, by the Central Statistics Office (CSO).

The National Equality Data Strategy 2026-2031

The National Equality Data Strategy was developed as the framework to support the collection and use of equality data by Government Departments and to develop the necessary standardisation, guidance and capacity building to support this process.

Equality data refers to *"any piece of information that is useful for the purposes of describing and analysing the state of equality"*.

Data that is analysed and reported by equality grounds, such as disability, can highlight where a particular service user may not be able to adequately access the services we are providing. It also aids us in measuring compliance with our obligations to promote equality and protect human rights in Ireland.

The National Human Rights Strategy for Disabled People commits to a more strategic and coordinated approach to disability research and data, working in line with this National Equality Data Strategy.

International Best Practice in Statistics for Disability Measurement

It is the intention that the Irish Disability Survey would follow best international practice in terms of survey design and concept. In this regard, key international benchmarks are the International Classification of Functioning, Disability and Health (ICF), and the United Nations Washington Group on Disability Statistics.

The International Classification of Functioning, Disability and Health (ICF) Framework

The IDS will be informed by the International Classification of Functioning, Disability and Health (ICF), as recommended by DCDE, the NDA, and the wider IDS Steering Group. The ICF is the World Health Organisation's (WHO) framework for measuring health and disability at both individual and population levels. This framework has been ratified by all WHO member states, including Ireland. The ICF explains disability

as an interaction between a person's impairments (limitation in functioning) and environmental barriers that may limit their participation in society. This is consistent with the social model where the disability is caused by barriers in society rather than the person's impairment.

In order to examine the impact of such barriers, the population at risk of disability due to societal barriers need to be identified. Otherwise, it would be impossible to tease out how policies and barriers affect the inclusion of disabled people.

Washington Group on Disability Statistics

This group established by the UN has involved representatives of national statistics offices, relevant international organisations, and DPOs.

By focusing data collection on those who have difficulty in carrying out basic, universal activities, it seeks to identify those who would be at greater risk than the general population of social exclusion if their environment was unaccommodating, for example, those unable to access education or employment.

Human Rights Based Approach to Data

The UN published a guidance note which provides general advice and guidance on elements of a common understanding of a Human Rights-Based Approach to Data. The guidance note specifically focuses on the issues of data collection and disaggregation. Disaggregation is where data is analysed and broken down by specific variables such as age, gender, or geography.

A preliminary set of main principles, recommendations and good practices are set out under the following headings: participation, data disaggregation, self-identification, transparency, privacy, accountability.

Appendix 2: IDS Steering Group Membership

Representing Bodies on the IDS Steering Group
Department of Children, Disability and Equality (chair)
Central Statistics Office
Department of Education and Youth
Department of Health
Department of Social Protection
Department of the Taoiseach
Department of Transport
Disability Federation of Ireland
Disabled Person's Organisation Network
Economic and Social Research Institute
Health Research Board
National Disability Authority

Appendix 3: IDS Subgroup Membership

Representing Bodies Across the IDS Subgroups
ADHD Ireland
AsIAm
Chime
Central Statistics Office
Department of Children, Disability and Equality*
Department of Education and Youth
Department of Finance
Department of Further and Higher Education, Research, Innovation and Science
Department of Social Protection*
Department of Transport*
Disability Federation of Ireland
Disabled Women Ireland
Disabled Person's Organisation Network
Dyslexia Ireland
Dyspraxia Ireland
Enable Ireland
European Disability Forum
FASD Ireland
Health Research Board
Health Service Executive*
IBEC
Independent Living Movement Ireland
Irish Congress of Trade Unions
Maynooth University
Middletown Centre
National Council for Special Education
National Rehab Hospital
National Disability Authority*
Neurodiversity Ireland
Neuropride Ireland
University College Dublin
University of Limerick
Vision Ireland
*Served as subgroup co-chair with the CSO

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