

The benefits of an ICF-aligned NDIS data structure

August 2023

Introduction and recommendations

This submission builds on our previous submission titled *Using the ICF to underpin NDIS information* (see Attachment 1). In that submission we proposed that the World Health Organization's (WHO) International Classification of Functioning, Disability and Health (ICF) should be used as the basis for developing a comprehensive National Disability Insurance Scheme (NDIS, 'the Scheme') data structure, to facilitate the more effective and transparent use of, and guide improvements to, NDIS data.

In this submission we make the following key points and recommendations:

1. Currently, data captured through the Scheme are not adequate to answer the five questions posed by the NDIS Review in the 'What we have heard' report.¹
2. A comprehensive NDIS data structure should be developed as a matter of priority. All data captured through the Scheme would be located within this structure.
3. The ICF concepts and classifications should be used for developing NDIS data items relating to functioning and disability.
4. A properly resourced data development project should be undertaken, following established approaches and involving key stakeholder groups.
5. The objective of the data development project should be to ensure that data captured through operation of the Scheme meet the needs of participants and other stakeholders, and can be related to data from other sources, including survey and administrative data.

An NDIS data structure

Data captured through the Scheme are not adequate to answer key questions posed by the NDIS Review and other stakeholders.

To have a clear understanding of data captured through the Scheme, a structure is needed within which all data items can be located. An NDIS data structure would group data items under meaningful headings. It would show clearly how data items relate to each other and to points in the participant pathway (Figure 1).

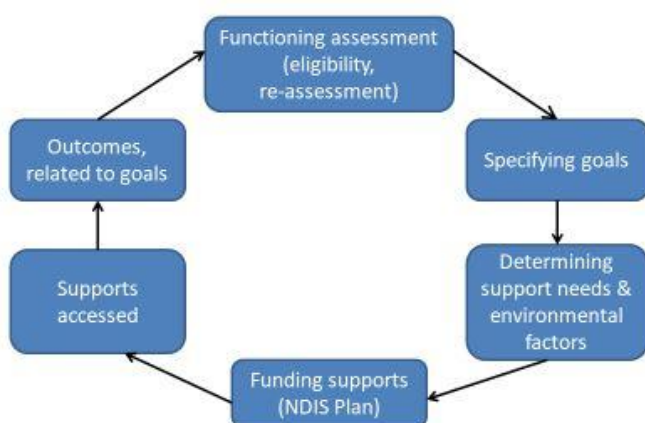


Figure 1: Key data capture points on NDIS participant pathway

¹ The 'What we have heard' report identifies five key challenges: Why is the NDIS an oasis in a desert? What does reasonable and necessary mean? Why are there many more children in the NDIS than expected? Why aren't NDIS markets working? How do we ensure that the NDIS is sustainable?

An NDIS data structure would:

- **Strengthen NDIS data:** clearly defining data items, and relating them to points in the participant pathway, would help identify gaps and where data improvements are needed.
- **Improve transparency and communication:** all stakeholders would have a common understanding of what data are captured and the underpinning data concepts; data item definitions would use common terminology.

There is extensive experience in developing administrative data collections and clinical registries in Australia. Expertise and resources held by Australian Government agencies, including the Australian Bureau of Statistics (ABS), the Australian Institute of Health and Welfare (AIHW), and the Australian Commission on Quality and Safety in Health Care should be drawn upon to guide the development process.²

Using the ICF to develop NDIS data

The ICF is an international data standard, and has underpinned disability data development in Australia for over 20 years.³ It provides a comprehensive framework and standardised terminology for capturing and relating information on all aspects of functioning and disability, including environmental factors and personal factors that affect functioning (Figure 2).

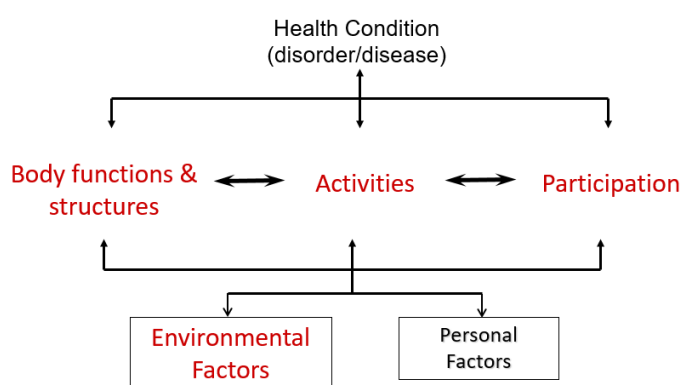


Figure 2: ICF model showing interactions between the components

The ICF provides:

Conceptual clarity – definition of key concepts, such as impairment, activity, participation, and environmental factors (barriers or facilitators).

Classifications – hierarchically structured sets of domains for body functions and structures, activities and participation, and environmental factors.

² See for example: [AIHW 2023, Standardising aged care data: Technical report on the development of an Aged Care National Minimum Data Set](#); [AIHW 2007, A guide to data development](#); [Australian Health Care Quality and Safety Commission 2022, Framework for Australian clinical quality registries, Second Edition – consultation version](#).

The AIHW's Metadata Online Registry ([METEOR](#)) has a [Disability data dictionary](#), which 'provides a reference set of data standards for collection of data from specialist disability service providers and other service providers delivering basic community care'.

³ For a concise history of disability data development in Australia, see: Madden and Madden 2019. Disability services and statistics: Past, present and future. In [Australia's Welfare 2019 Data Insights](#); Australian Institute of Health and Welfare, Ed.; AIHW: Canberra, Australia.

ICF concepts and classifications can support NDIS data development relating to:

- **Participant functioning, goals and outcomes in different domains**, including participation and participation restrictions (e.g., vocational training), activities and activity limitations (e.g., speaking), impairments of body function and structure (e.g., vision impairment).
- **Environmental factors relevant to the participant's functioning**, including aspects of a person's situation that affect their functioning and need for support (e.g., lack of accessible public transport), and the supports funded and accessed (e.g., assistance with transport).
- **Measurement constructs and scales**. ICF provides for recording the extent of impairment or the extent of difficulty in activities or participation using a scale from 0 to 10. Additional measures for describing activities and participation have been developed for use in Australian data collections: Difficulty; Need for assistance; Extent of participation; Satisfaction with participation.

It would be desirable also to review and amend sections 24, 25 and 33 of the NDIS Act 2013 so that the disability and early intervention requirements for accessing the Scheme, and requirements relating to the participant's plan, are expressed in ICF-aligned language. This would enable the data captured through the Scheme to be clearly related to the Act.

How ICF-aligned NDIS data would help answer key questions

The NDIS Review's 'What we have heard' report sets out five 'key challenges'. The questions posed in the report provide a good starting point for thinking about what data are needed and for demonstrating the value of the ICF. We use the questions as headings below, and discuss how improved NDIS data, aligned with ICF concepts, would help to address each of these.

Why is the NDIS an oasis in a desert?

Data are needed that enable an understanding of the supports accessed by people with disability both through NDIS plans and outside of the Scheme. Ideally, it should be possible to compare and relate NDIS data, data about mainstream services, and national survey data. An ICF-aligned NDIS data structure with well-defined data items will make it clear how NDIS data can be used with information from other key sources, such as the ABS Survey of Disability, Ageing and Carers and administrative data (e.g., health, aged care, education), to answer questions such as:

- How are the needs of students with disability assessed and met in education systems compared to the NDIS?⁴
- How does the functioning profile of NDIS participants compare with the functioning profile of people with disability who are not NDIS participants?
- Looking at supports for accessing employment provided to people with disability through the NDIS and outside of the NDIS, is there duplication or are there gaps, in terms of geography, age, and functioning profile?

What does reasonable and necessary mean?

Consideration of what is 'reasonable' and 'necessary' could be informed by comparing NDIS participants with the general population in relation to participation in life areas. The United Nations Convention on the Rights of Persons with Disabilities enshrines the rights for people with disability to participate in all aspects of life on an equal basis with others. The ICF states that 'the presence of a participation restriction is determined by comparing an individual's participation to that which is expected of an individual without disability in that culture or society'. Therefore, for example, ABS survey data about access to transport, participation in education, and participation in social and cultural activities for the general population could be used as a benchmark when determining what supports may be required to mitigate a person's participation

⁴ Note that the Victorian Department of Education's newly developed Disability Inclusion Profile is based on the ICF: [Supporting information guidance for schools](#).

restrictions, whether these supports are accessed through community-based 'Tier 2' services or as 'reasonable and necessary' supports funded through an NDIS plan.

In addition, capturing participant data on functioning (activities and participation in different life areas), goals, relevant environmental factors (e.g., products and technologies, geography) and supports in a standard way would make it possible to examine variation within and between different cohorts of participants. This would provide insights into the extent to which the Scheme is operating in an equitable and sustainable way.

Why are there many more children in the NDIS than expected?

Relating ICF-aligned NDIS data to key population and administrative data would provide insights into questions such as:

- What is the profile of children in the NDIS, in terms of demographics (personal factors), environmental factors (e.g., geography, family type), and functioning (e.g., impairments, activity limitations and participation restrictions)?
- How does this compare with the profile of children with disability who are not NDIS participants (in the ABS Survey of Disability, Ageing and Carers), and children with disability receiving other services (e.g., support through education systems)?
- How does this compare with the profile of children who received support through disability services before the NDIS (using data from the Disability Services National Minimum Dataset)?
- What supports are accessed through mainstream service systems (e.g., health, education) by children with disability who are NDIS participants compared with those who are not NDIS participants (e.g., using linked data in the National Disability Data Asset).

Why aren't NDIS markets working?

We know that, in some sectors, services have changed since the NDIS was introduced. For example, for people with psychosocial disability, services available outside the NDIS are now predominantly health-related rather than social services, and a lack of service funding stability impacts supply and human resources.⁵ Addressing questions on NDIS markets will require information about:

- What supports (environmental facilitators) participants purchase with their NDIS plans, and from what types of providers.
- What supports funded in plans are accessed at higher/lower rates, and factors associated with these differences.
- Environmental and personal factors associated with variation between participants in plan utilisation and supports purchased.
- Characteristics of the workforce providing NDIS supports, and comparison with the wider workforce.
- Informal supports received by NDIS participants.
- Supports received by NDIS participants through mainstream services.
- Environmental changes funded through NDIS plans (e.g., home modifications).
- What services are available to NDIS participants and people with disability not in the NDIS.

An ICF-aligned NDIS data structure could be used to show clearly what relevant Scheme data currently exist. Data gaps may be addressed by linking NDIS data with other data sources or capturing additional data on supports through the Scheme.

⁵ See, for example, pre- and post-NDIS service mapping in the psychosocial sector: [The Integrated Atlas of Psychosocial Care in the Western Sydney Primary Health Network Region](#)

How do we ensure that the NDIS is sustainable?

To date, there has been insufficient transparency concerning what data are used and how they are used to produce projections of participant numbers, participant profiles, and costs. Adequate information about the quality and appropriateness of the data has not been made available and the assumptions underpinning the projections have not been sufficiently articulated and justified. This hampers external scrutiny and interrogation of the methods used and conclusions drawn concerning projected costs and Scheme sustainability.

An NDIS data structure would help identify where improved data are needed to enable all factors that influence Scheme costs to be included, in order to produce more reliable and understandable projections.

For example, in the 'What we have heard' report, the focus on diagnosis rather than support needs as a basis for grouping NDIS participants has been identified as a problem. Using data on functioning, captured in a standard way, would provide a more sophisticated and relevant basis for grouping participants in the context of modelling expected changes in participant profile and costs over time.

Developing an ICF-aligned NDIS data structure – how should the work proceed?

An ICF-aligned NDIS data structure should be developed through an adequately resourced data development project and involve key stakeholder groups, including:

- people with disability and their representative organisations;
- the National Disability Insurance Agency (NDIA) and policy makers representing key service sectors (e.g., disability, health, aged care, education);
- statistical agencies (AIHW, ABS);
- disability data development experts with strong knowledge of ICF;
- researchers with experience analysing disability data;
- NDIS planners and disability service providers.

As noted above, administrative data development is a well-trodden path, and there are precedents and expertise available to inform this work.

The work should encompass:

- Clear statement of the operational, planning and policy requirements for NDIS data. All stakeholders should be involved in identifying key questions and related data items at each step of the participant pathway (Figure 1).
- A technical review of data currently captured through the Scheme, using ICF as a framework for this review in relation to data about functioning, goals, support needs, supports, and outcomes.
- Review of how data are captured in other key national data sources with which NDIS should be relatable (e.g., ABS Survey of Disability, Ageing and Carers; health and education administrative data).
- Design of a fit-for-purpose data structure that relates data captured to operation of the Scheme 'on the ground', particularly key points in the participant pathway.
- Defining underpinning data concepts (utilising ICF definitions wherever relevant) and relationships between data items.
- Development of a publicly available NDIS data dictionary and metadata resources.
- Identification of data gaps and consideration of how these could be addressed (e.g., capturing additional data through the Scheme, or linking NDIS data with other existing data sources).

The value of quality, fit-for-purpose NDIS data for informing improved operation of the Scheme and disability policy and programs more broadly will be magnified in the context of linked data environments, including the National Disability Data Asset. As for all data about individuals, protecting privacy and confidentiality is of utmost importance.

As with any data development process, it will be necessary to balance the costs of data collection to all concerned against the value gained. Further, developing data is never merely a technical endeavour: there must always be consideration of the cultural, social, political and ethical dimensions, and the implications for those to whom the data relate. Crucially, people with disability and their representative organisations must be key players in the development of disability data and statistics, and in their use.

Conclusion

The NDIS Review ‘What we have heard’ report highlights key areas where data on the operation of the NDIS are missing or not adequate. We propose a comprehensive data development plan which adopts the ICF as an underpinning framework. The use of ICF concepts and classifications is crucial to ensure that data on functioning and related environmental factors are captured in a way that meets key information needs and enables comparison of NDIS data with other Australian and international data sources relevant to the provision of supports to people with disability.

Further information about use of the ICF to support NDIS data and operation of the Scheme

The ICF Australia Interest Group (ICF-AIG) is a collaborative, multidisciplinary group of people who have diverse expertise in data development and the ICF and its uses. The ICF-AIG paper titled *The ICF and its potential uses in the National Disability Insurance Scheme (NDIS)* (see Attachment 2) was provided to the NDIA in April 2022. It sets out the role and value of the ICF to develop new and valid approaches for assessment and outcomes measurement for NDIS participants, and for developing a comprehensive NDIS data structure. It contains links to other key ICF-related resources.

The ICF-AIG would be happy to provide further input to the Independent Review Panel concerning data development and potential uses of the ICF in the NDIS.

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Attachment 1: Using the ICF to underpin NDIS information

Attachment 2: The ICF and its potential uses in the National Disability Insurance Scheme (NDIS)

Using the ICF to underpin NDIS information

Submission to the NDIS Review

In this submission, we propose that the International Classification of Functioning, Disability and Health (ICF) should be used as the basis for developing a comprehensive NDIS data structure, to facilitate the more effective and transparent use of, and guide improvements to, NDIS data.

We refer the Independent Review Panel to the attached paper: *The ICF and its potential uses in the National Disability Insurance Scheme (NDIS)*.

What is the ICF?

The ICF is a World Health Organization framework and classification system for organising and documenting information on functioning and disability. It is an international standard and has underpinned disability data development in Australia for over 20 years.

The ICF is well aligned with the UN Convention on the Rights of Persons with Disabilities (CRPD) – the two instruments share common concepts and terms (e.g., environment, barriers, participation) and ICF domains correspond well to Articles of the CRPD.

Importance of NDIS data

Data on NDIS participants are crucial for supporting operation of the scheme and ensuring that it delivers outcomes for individuals. Such data include measures of function, goals, support needs, supports funded and accessed, outcomes (e.g., social and economic participation), personal factors (e.g., participant demographics) and environmental factors (e.g., access to informal care, availability of transport).

At an aggregate level, statistical analysis of NDIS data is essential for telling users and funders what the NDIS is delivering, and for informing improvements to scheme implementation. Analyses investigating, for example, relationships between supports accessed and outcomes achieved for different cohorts can potentially inform improvements to scheme effectiveness.

The value of NDIS data as a longitudinal administrative data source is magnified in the context of linked data environments, including the proposed National Disability Data Asset.

NDIS data are also essential for informing disability policy and programs more broadly. Relating (or linking) NDIS data to other administrative data sources can enable investigation of the interfaces between the NDIS, mainstream services, and other disability supports. Such analyses could describe the characteristics of people with disability who are accessing different programs and services, and provide insights into unmet need.

Need for an NDIS data structure

With NDIS sustainability in the spotlight, and a renewed emphasis on scheme outcomes and effectiveness, it is time to review information needs, what data are collected and how, and how data are analysed to monitor scheme performance and inform improvements.

Further development of NDIS data to better meet information needs should take place in the context of a comprehensive, overarching NDIS data structure. Undertaking separate, disconnected data development exercises risks producing data on different aspects of the scheme that cannot be used effectively together.

The ICF is the appropriate framework to use as a basis for developing a coherent data structure for the NDIS, within which to locate both quantitative and qualitative data captured at different points in the participant journey relevant to function, goals, support needs, supports funded and accessed, outcomes, personal factors and environmental factors.

Benefits of an NDIS data structure based on the ICF framework

Having such an overarching data structure would assist stakeholders to understand what information is being captured, how data from different sources may be related and used together, and where there are data gaps. It would support effective use of data for cost-benefit analyses, modelling and projections, and evaluating equity in resource allocation. Using the ICF in this way would also facilitate relating NDIS data to other population data sources relevant to people with disability (e.g., Australian Bureau of Statistics survey data).

Locating NDIS data within an overarching data structure could support sophisticated statistical analysis, clear understanding of data limitations, and identification of data gaps and where data development is needed.

An agreed data structure would improve data transparency, which is vital for restoring and maintaining trust in the NDIS. Having all NDIS data located within a data structure and underpinned by ICF concepts would support common understanding of data items and underlying data concepts used in modelling and projections. This would facilitate informed discussion about scheme sustainability and critical appraisal by independent experts.

Further information about use of the ICF to support NDIS data improvements

The ICF Australia Interest Group (ICF-AIG) is a collaborative, multidisciplinary group of people who have diverse expertise in the ICF and its uses. The ICF-AIG has prepared the attached paper: *The ICF and its potential uses in the National Disability Insurance Scheme (NDIS)*.

This paper was provided to the NDIA in April 2022. It sets out the role and value of the ICF to develop new and valid approaches for assessment and outcomes measurement for NDIS participants, and for developing a comprehensive NDIS data structure. It contains links to other key ICF-related resources.

The ICF-AIG would be happy to provide further input to the Independent Review Panel concerning the ICF and its potential uses in the NDIS.

Nicola Fortune, Ros Madden, Richard Madden and Catherine Sykes

February 2023

April 2022

The ICF and its potential uses in the National Disability Insurance Scheme (NDIS)

A technical paper of the International Classification of
Functioning, Disability and Health Australia Interest
Group (ICF-AIG)

The ICF and its potential uses in the NDIS

A technical paper of the International Classification of Functioning, Disability and Health Australia Interest Group (ICF-AIG)

Introduction and purpose of this document

The International Classification of Functioning, Disability and Health (ICF) is a framework and classification system for organising and documenting information on functioning and disability [1]. It conceptualises functioning as a 'dynamic interaction between a person's health condition, environmental factors and personal factors' (Figure 1). 'Functioning' is an umbrella term encompassing all body functions, activities and participation.

The ICF provides a standard language and conceptual basis for the definition and measurement of disability. It provides classifications for body functions, body structures, activities and participation, and environmental factors. The role of personal factors is acknowledged in the ICF, but the ICF does not provide a classification of personal factors. The ICF is designed to describe functioning and disability, *not* to classify people. (See Attachment 1: *Definitions and components of the ICF*)

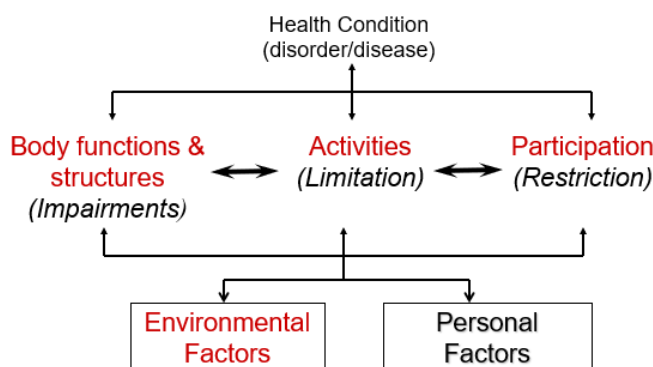


Figure 1: Interactions between the components of ICF

The International Classification of Functioning, Disability and Health Australia Interest Group (ICF-AIG) is a collaborative, multidisciplinary group of people who are interested in the ICF and have diverse expertise in the ICF and its uses. The ICF-AIG meets several times each year to discuss matters of mutual interest.

The ICF is referred to in the [National Disability Insurance Scheme \(Supports for Participants\) Rules 2013](#) (Part 4 Needs assessment) and the [National Disability Insurance Scheme \(Becoming a Participant\) Rules 2016](#) (Part 7 Assessing whether a person meets the disability or early intervention requirements). Both instruments include the statement: "A tool must ... have reference to areas of activity and social and economic participation identified in the World Health Organisation International Classification of Functions, Disability and Health as in force from time to time."

This technical paper has been prepared by members of the ICF-AIG:

- To inform the program of work and associated co-design activities towards development of a new National Disability Insurance Scheme (NDIS) person-centred assessment model.
- To set out the role and value of the ICF in the context of potentially developing new and valid approaches for assessment and outcome measurement for NDIS participants.
- To articulate principles to guide the use of the ICF in developing a new person-centred assessment model, including developing and evaluating possible assessment tools.

Additional information is provided in three attachments:

1. Definitions and components of the ICF
2. Mapping assessment tools using ICF
3. Ethical guidelines for the use of ICF

A list of ICF-AIG members who have contributed to and endorsed this document is provided at the end of this document.

The ICF and its potential uses in the context of the NDIS

The ICF is well placed to support development of a person-centred assessment model to underpin fairer and more consistent NDIS access and planning. Importantly, it provides a structured approach for taking into account the determining role of the environment in helping or hindering participation across all areas of life. The ICF is an international standard, and was developed with involvement of people with disability and their representative organisations [2, 3].

The ICF represents a biopsychosocial model of disability, combining the medical and social models of disability. The ICF and United Nations [Convention on the Rights of Persons with Disabilities](#) (CRPD) share common concepts, culture and terms (e.g., environment, barriers, participation), and the subject matter of rights in the CRPD can readily be mapped to the ICF domains, demonstrating broad commonality of content.

Four principles underpinned and guided ICF development and remain key characteristics of the ICF [1, 4]:

- **Universality:** ICF is about all people and is relevant to everyone's functioning. It is not a tool for labelling minority groups.
- **Aetiological neutrality:** the language and structure of the classification make it relevant to any health condition.
- **Neutral language:** wording and domain names allow users to express both positive and negative aspects in each area of functioning (e.g., d455 'Moving around' could be used to express a limitation, a goal for improved functioning, or an area in which functioning has improved over time).
- **Environmental factors:** ICF provides a classification of physical, social and attitudinal factors that may affect functioning across all areas of life.

Access to the NDIS

The disability requirements for NDIS access set out in s.24 of the NDIS Act include the need to establish:

- Disability that is attributable to an impairment (s24(1)(a))
- Substantially reduced functional capacity to undertake, or psychosocial functioning in undertaking: communication; social interaction; learning; mobility; self-care; self-management (s24(1)(c))
- Impact on the person's capacity for social or economic participation (s24(1)(d)).

The early intervention requirements (s25) include the need to establish impairment and that the provision of early intervention supports is likely to benefit the person by reducing their future needs for supports.

The ICF classifications of Body Functions and Body Structures can be used to describe impairments.

The ICF classification of Activities and Participation can be used to describe functional capacity in each of the activity areas specified in s24(1)(c) and participation restrictions in social and economic life areas.

The ICF classification of Environmental Factors, and its conceptual approach for understanding how environmental factors can be facilitators of or barriers to functioning across different areas of life, are clearly relevant to the assessment of early intervention requirements.

Planning

Section 33 of the NDIS Act specifies that a participant's plan must include a statement, prepared by the participant, that includes:

- their goals, objectives and aspirations;
- their environmental and personal context (including living arrangements, informal supports, social and economic participation).

It must also include a statement of the reasonable and necessary supports that will be funded under the NDIS.

The ICF classification of Activities and Participation is of particular relevance for describing a person's goals, objectives and aspirations across all relevant life areas (as determined by the person).

Supports will generally relate to environmental factors (e.g., assistance, assistive devices, equipment, environmental modifications, including the removal of barriers) to support functioning in particular areas of life (or across multiple areas) and to build capacity, in line with the NDIS insurance principles. Therefore, the ICF classifications of Environmental Factors and Activities and Participation are of very significant relevance for describing such supports.

For example, an NDIS participant may have the goal of participating in a sporting team (d9201 Sports); reasonable and necessary supports to facilitate this might include adapted sporting equipment (e1401 Assistive products and technology for culture, recreation and sport) and assistance to influence the attitudes of team members to be more inclusive (e425 Individual attitudes of acquaintances, peers, colleagues, neighbours and community members). ICF Environmental Factors Chapter 3, 'Support and relationships', can be used to describe who provides support and assistance (e.g., e310 Immediate family, e340 Personal care providers and assistants).

Outcomes

Measurement of participant outcomes is important at the individual level, to determine the extent to which their plan is effective in helping them achieve their stated goals, including capacity building. Outcome measurement is also essential at scheme level, as a critical component of cost-benefit analyses and to generate data for accountability reporting and modelling and projections.

Outcomes can be measured:

- in relation to the person's goals, objectives and aspirations (as stated in their plan), and
- in relation to a set of outcome domains common across all participants.

The ICF classification of Activities and Participation is of particular relevance for outcome measurement.

Assessment tools

NDIS assessments conducted for access (to determine eligibility), planning (to determine reasonable and necessary supports related to goals), and outcome measurement entail the use of assessment tools. In selecting appropriate assessment tools, consideration should be given to evidence of tool reliability and validity in the NDIS context [5].

In developing a person-centred approach for assessment, uses of the ICF would include:

- Mapping assessment tools being considered for use, to determine whether they provide adequate coverage of relevant NDIS and ICF domains.
- Identifying 'gaps' – domains not adequately covered by assessment tools currently in use.
- Development of new or enhanced assessment tools.

See Attachment 2: *Mapping assessment tools using ICF*

Aspects of functioning and environmental factors addressed by assessment tools can be mapped to ICF domains (chapters and more detailed codes) in the ICF classifications of body functions, body structures, activities and participation, and environmental factors.

The measurement constructs used in particular tools (e.g., degree of difficulty, frequency of need for assistance) should be considered in relation to the purpose for which the assessment is being conducted [6].

Scales or categories used to measure functioning can be mapped to the qualifiers in the ICF: extent or magnitude of a ‘problem’ and degree of difficulty (see Attachments 1 and 2).

A mapping table (or similar product), showing how a range of different assessment tools relate to ICF domains would be a valuable resource for all those involved in assessment and planning processes. It could include tools commonly used by health practitioners, to help determine whether assessments conducted adequately cover all aspects required for a particular participant. It could potentially be used to relate assessment tools to a specified minimum set of assessment information required for the planning process (e.g., with reference to the resource benchmarks, as described below).

More generally, the ICF conceptual model and classifications can be used as an underpinning framework for the program of work and associated co-design activities to assist with developing a new NDIS person-centred assessment model. It would help to get everyone ‘on the same page’ and taking a common conceptual approach for thinking about functional capacity, goals, supports and resourcing in the context of the NDIS.

Data

The ICF has underpinned disability data development in Australia for over 20 years [7]. It provides a comprehensive framework for capturing and relating information on all aspects of functioning and disability. The ICF could be used to develop an encompassing data structure for the NDIS, within which data relevant to access, goals, support needs and outcomes for participants could be located. This would assist all stakeholders to understand what information is being captured, how data from different sources may be related and used together, and where there are data gaps. An ICF-based NDIS data structure would support the more effective use of data for cost-benefit analyses, modelling and projections, and evaluating equity in resource allocation and outcomes to support strategic decisions to ensure scheme effectiveness and sustainability. Using the ICF in this way would also facilitate relating NDIS data to other population data sources relevant to people with disability (e.g., Australian Bureau of Statistics survey data).

Co-designing equitable allocation of resources to NDIS participants

A person-centred assessment model must be able to deliver fair decisions, equitable resource allocation and scheme sustainability. For an individual participant, reasonable and necessary supports to be funded by the NDIS should be determined with regard to people’s functional capacity¹, their goals, and their environmental and personal context.

To ensure that the NDIS is both equitable and sustainable, a key aim of the co-design process should be the development of transparent resourcing benchmarks relating to plan size. Such benchmarks would be designed to guide the quantum of funding within a plan for reasonable and necessary supports.

The ICF would provide a sound framework on which to base the development of resourcing benchmarks. Having a common framework will be important to support discussions among all stakeholders, including the NDIA, about participants’ reasonable and necessary supports and related resourcing benchmarks.

To ensure sound and transparent links between the assessment of support needs (during the planning stage) and the benchmarks guiding the quantum of funding awarded, the co-design process may need to specify a minimum set of assessment information that each participant must have, and ensure that each participant has the means to obtain the required assessments. The NDIA’s requirements should be ICF-based, so that participants, assessors and the NDIA are using a common set of domains when involved in the decision process.

¹ “Functional capacity refers to an individual’s ability to be involved in life situations and to execute tasks or actions, with and without assistance (assistive devices and/or personal assistance). Information regarding impairment(s) and environmental factors, and how they impact the individual’s function is included when assessing functional capacity.”
Source: National Disability Insurance Agency. Assessment of Functional Capacity for NDIS – Development and Framework. August 2020.

Principles to guide use of ICF in developing a person-centred assessment model

The ICF, when first published, set out general principles on which the ICF was based (see the four principles above: Universality, Aetiological neutrality, Neutral language, and Environmental factors) and also ethical guidelines for use. Both the ICF and its ethical guidelines for use were the product of more than a decade of collaboration across the world, involving people from many disciplines and backgrounds including those with lived experience of disability.

Ethical guidelines for the use of ICF are set out in Annex 6 of the ICF (see Attachment 3: *Ethical guidelines for the use of ICF*). These guidelines provide foundational principles that are in line with person-centredness, co-design and transparency – principles acknowledged as central to the development of a new NDIS person-centred assessment model.

- **The foundational ethical principles for use of the ICF** include that:
 - the person with disability should be involved in and aware of any use of the ICF, whether service-oriented or research-oriented;
 - in clinical or service-oriented uses, the ICF should always be used with the full knowledge, participation and consent of the person with disability;
 - information recorded should be viewed as personal information and accorded all the recognised rules of confidentiality.

These principles should guide use of the ICF itself in the NDIS context, and also use of assessment tools for NDIS access and planning processes. Ensuring that the assessment tools and processes are aligned with these principles is enabled by using a tool such as the ICF, according with these principles and built on the overarching principle that: the person is involved in and guides all key processes – goal setting, articulating needs, deciding supports, evaluating outcomes.

In addition to these foundational ethical principles, we propose the principles below, drawn from the ICF itself and developed through experience of its use, to guide use of ICF in developing a person-centred assessment model.

The following such principles are derived directly from the ICF:

- **Any assessment for NDIS access or planning purposes should take environmental factors into account.** Environmental factors may affect any area of functioning. The person's view (and the views of their trusted supporters, where appropriate) is paramount in understanding the extent to which an environmental factor is a facilitator or barrier for any area of functioning or their life overall [1] (pp 232-33); [4] (p.25).
- **A person-centred assessment model must recognise the dynamic nature of disability.** The ICF conceptualises functioning and disability as a dynamic interaction between health conditions, environmental factors, and personal factors (Figure 1). Understanding how a person's functioning and support needs may vary over time and place is an essential input to equitable and effective access and planning assessment. In assessing disability-related needs it is also essential for assessment tools to be able both to capture, and respond to, the possible dynamic effects of health conditions that often have a variable temporal course. Considering ICF-based assessments together with health condition assessment allows for such a holistic understanding².

Assessments need to be made in awareness of potential variations over time and place. Decisions are needed about when assessment is of most benefit to the person concerned, and in what environment,

² The International Classification of Diseases (ICD) is the World Health Organization's classification of causes of mortality and morbidity; it sits alongside the ICF as a member of the WHO's Family of International Classifications.

and about when repeat measures are best used to inform outcome measurement and to monitor progress and variation along the way.

- **Assessments should take relevant personal factors into account, including cultural factors.**

Personal factors may also influence functioning, although they are not defined and classified in the ICF. These include factors such as gender, ethnicity and lifestyle. The recognition of ethnicity and related cultural factors needs particular attention in a multicultural country such as Australia, and there are experts who can advise on how best to do this. Enabling organisations such as the National Ethnic Disability Alliance (NEDA) and First Peoples with Disability Network Australia (FPDN) to advise on appropriate involvement of such cultural experts should be part of the co-design of a new person-centred assessment model.

Further principles for ICF use have since been spelled out, based on experience in the twenty-plus years since its publication. Principles derived from practice and evidence, as well as misuse of the ICF, include:

- **Assessment must meet the challenge of combining information from various sources.**

Operationalising the ICF framework and principles requires that assessment must combine and balance quantifiable information obtained using scientific standards with the expert knowledge of the person living with disability and the family members, carers and professionals who know and understand them. Assessors who do and do not know the person may have varying insights and opinions that need to be shared and balanced. The person, together with trusted members of their support network, is best placed to determine their priorities for participation and related support needs. Assessors should be appropriately trained and expert in the use and limitations of the tools, and who are capable of exercising good judgement.

- **Participation should be understood and assessed in the environmental contexts of the areas of life important to the person.**

The ICF definition of Participation, ‘involvement in a life situation’, entails consideration of the area of life in which a person is participating and also how they feel about it. Analysis of practice, before and after ICF publication, has shown that “participation ... represents a transformational concept that requires new, dynamic measures collected in context” [8] (p.224).

As the goals, objectives and aspirations specified in a participant’s NDIS plan relate to participation in areas of life important to that person, participation should be the starting point for assessment to determine reasonable and necessary supports. Participation should be assessed in the environmental contexts of the areas of life important to the person.

Understanding Participation in the context of someone’s life demands a thorough appreciation of the environmental contexts in which they live their life and, as such, relevant environmental factors should be considered for incorporation into assessment (Kellest, pers comm 4 March 2022).

- **Assessment should span all life areas of importance to the person**

Specifying assessment tools and processes for use in a large and diverse population requires tools that span all areas of life defined by the ICF [9]. All Activities and Participation chapters, with no omissions, are needed for assessment tools relevant for diverse populations; support needs in one domain (or a limited set of domains) cannot be used to predict support needs in other domains.

- **Diagnosis alone does not demonstrate disability**

Assessment of a person’s functioning and disability must not be made solely on the basis of their health condition(s). Information about a person’s health condition(s) is often relevant for understanding their situation. In some cases, diagnostic information may indicate areas of functional capacity likely to be affected, and some diagnostic tools (e.g., for spinal cord injuries) capture information about functioning. However, the linear, causal model, and the related practice of inferring the presence of disability based only on a person’s diagnosis, have been superseded by the interactive ICF model. For example, a diagnosis of autism spectrum disorder alone does not indicate the extent of any disability. Regardless of

whether the person has a particular diagnosis, or an unknown health condition, assessment should be conducted to determine their functioning and support needs.

- **Accept and work with the complexity of assessment**

The NDIS spans a large and diverse participant population. Co-design of a person-centred assessment model that ensures fair decisions and equitable resource allocation is a complex task.

Assessment tools used must be appropriate to the circumstances of individual participants. A selection of different assessment tools may be needed. Use of a 'one-size-fits-all' tool across the diversity of NDIS participants may result in inequitable resource allocation, because such a tool will 'fit' some participants better than others. If different tools are to be used for different groups of participants, it must be possible to relate the measures produced by different tools to a common framework of domains and a common measurement scale to ensure equitable decision-making. ICF can provide a basis for both the common framework of domains and common measurement scale (See 'Assessment tools', above, and Attachments 1 and 2.) Further, if multiple tools are used for any one person, a common framework and common scale will enable information to be combined from various sources (see above principle 'Assessment must meet the challenge of combining information from various sources').

These principles for ICF use in the context of the NDIS and assessment must be applied alongside other general rules for the construction of assessment tools. For example, psychometric properties (such as reliability and validity) of assessment tools should be demonstrated in relation to the specific NDIS context in which the tool is to be used (including characteristics of participants such as age, gender and cultural background) [5].

The [ICF Practical Manual](#) is an invaluable resource to guide use of the ICF, and provides examples and case studies to illustrate use of the ICF in a range of contexts [10].

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Attachment 1: Definitions and components of the ICF

Box 1: Definitions of the components of the ICF, and of functioning and disability

Body functions - The physiological functions of body systems (including psychological functions).

Body structures - Anatomical parts of the body such as organs, limbs and their components.

Impairments - Problems in body function or structure such as a significant deviation or loss.

Activity - The execution of a task or action by an individual.

Participation - Involvement in a life situation.

Activity limitations - Difficulties an individual may have in executing activities.

Participation restrictions - Problems an individual may experience in involvement in life situations.

Environmental factors make up the physical, social and attitudinal environment in which people live and conduct their lives. These are either barriers to or facilitators of the person's functioning.

Functioning is an umbrella term encompassing all body functions, activities and participation. It denotes the positive or neutral aspects of the interaction between a person's health condition(s) and that individual's contextual factors (environmental and personal factors).

Disability is an umbrella term for impairments, activity limitations and participation restrictions. It denotes the negative aspects of the interaction between a person's health condition(s) and that individual's contextual factors (environmental and personal factors).

Source: WHO 2001, pp. 3,8,10

Each ICF component is the subject of chapter containing hierarchical lists of codes, designed to be mutually exclusive and exhaustive. The chapter headings listed in Box 2 provide a broad indication of the scope and contents of the ICF. The nine chapters of Activities & Participation are intended to cover all areas of life for all people. The five chapters of the Environmental Factors comprise physical, social and attitudinal factors that affect functioning.

Qualifiers are measures recorded after the relevant ICF category. A uniform or 'generic' five-point qualifier scale is provided to record the extent of the 'problem' or difficulty, in relation to impairment, activity limitation and participation restriction. It is recognised that the generic qualifier requires calibration to relate its scale to existing measurement tools. The Environmental Factors qualifier uses both a positive and a negative scale, to indicate the extent to which an environmental factor acts as either a facilitator or barrier to a person's functioning.

Box 2: ICF components and chapters

<p>Body Functions:</p> <ol style="list-style-type: none"> 1. Mental functions 2. Sensory functions and pain 3. Voice and speech functions 4. Functions of the cardiovascular, haematological, immunological and respiratory systems 5. Functions of the digestive, metabolic, endocrine systems 6. Genitourinary and reproductive functions 7. Neuromusculoskeletal and movement-related functions 8. Functions of the skin and related structures 	<p>Activities and Participation:</p> <ol style="list-style-type: none"> 1. Learning and applying knowledge 2. General tasks and demands 3. Communication 4. Mobility 5. Self-care 6. Domestic life 7. Interpersonal interactions and relationships 8. Major life areas 9. Community, social and civic life
<p>Body Structures:</p> <ol style="list-style-type: none"> 1. Structure of the nervous system 2. The eye, ear and related structures 3. Structures involved in voice and speech 4. Structure of the cardiovascular, immunological and respiratory systems 5. Structures related to the digestive, metabolic and endocrine systems 6. Structure related to genitourinary and reproductive systems 7. Structures related to movement 8. Skin and related structures 	<p>Environmental Factors:</p> <ol style="list-style-type: none"> 1. Products and technology 2. Natural environment and human-made changes to environment 3. Support and relationships 4. Attitudes 5. Services, systems and policies

Source: WHO 2001, pp. 29-30

Attachment 2: Mapping assessment tools using ICF

As stated in the ICF Australian User Guide, “The ICF is not an assessment or measurement tool, but rather a framework and set of classifications on which assessment and measurement tools may be based and to which they can be mapped.”

Mapping can be done to show the relationship between concepts matched across two schemes, for instance, concepts in an assessment tool can be mapped to concepts in the ICF. Mapping can specify different types of relationship between matched concepts, for example, whether the concept in an assessment tool is ‘equivalent to’ or ‘broader than’ or ‘narrower than’ the concept to which it is mapped in the ICF, or whether there is a ‘complete’ or ‘partial’ match between two concepts, or no match [1-3].

Before conducting mapping, it is important to:

- **Clearly articulate the purpose** for which the mapping is being conducted, and the end product required.
- **Specify the mapping process and rules to be applied** (e.g., to guide how the mappers should make decisions about equivalence of meaning between concepts and how users should interpret the maps).

Different types of maps can be produced, such as concept³ and concordance maps⁴. Different mapping methodologies can produce different results, and mapping exercises are sensitive to the direction of the maps (e.g., from ICF to NDIS assessment tool or from the NDIS assessment tool to the ICF). The method used should be fit for purpose.

To promote quality, transparency and reliability of mapping studies, ‘linking rules’ have been developed as a guide for how to link clinical measures, health-status measures and interventions to the ICF [4, 5]. There is now a rich literature describing application of these ICF linking rules in mapping studies for different purposes. When mapping to or from the ICF, it should be decided at the outset what level of the classification is to be used. A broad-brush mapping could be conducted using ICF chapter headings; alternatively, more detailed mappings could be conducted using 3-digit or 4-digit codes within chapters.

Mapping an assessment tool to the ICF can show which areas of functioning are measured by the tool and which are not [6]. Mapping using the ICF framework has previously been conducted in the NDIS context and has demonstrated that the activities and social and economic participation components listed in sections 24 and 25 of the NDIS Act map to the nine ICF activities and participation chapters. No assessment tools were identified that are suitable for the scope of the NDIS which map to the whole ICF [6].

Future mapping could be undertaken to explore how a suite of assessment tools could be used together, to gather information on a person’s functional capacity across all ICF domains. Mapping tables produced would provide a way of showing clearly how specific tools relate to ICF domains, to guide decisions about their use. Results of mapping could also inform the development of new assessment tools better suited to NDIS requirements or enhancement of existing tools (e.g., to achieve more comprehensive coverage of ICF domains).

Any mapping of assessment tools for NDIS use should explicitly include environmental factors.

As well as mapping areas of functioning in assessment tools to ICF codes, there should be consideration of the measurement constructs used in different assessment tools (e.g., degree of difficulty, frequency of need for assistance) [7]. Scales or categories used to measure functioning can be mapped to the qualifiers in the ICF: extent or magnitude of a ‘problem’ and degree of difficulty.

³ Concept mapping relates whether all or partial concepts or terms are represented in the mapped codes.

⁴ Concordance mapping is a type of term mapping, which estimates percentages for term movements between categories within or across terminologies.

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Attachment 3: Ethical guidelines for the use of ICF

Respect and confidentiality

- (1) ICF should always be used so as to respect the inherent value and autonomy of individual persons.
- (2) ICF should never be used to label people or otherwise identify them solely in terms of one or more disability categories.
- (3) In clinical settings, ICF should always be used with the full knowledge, cooperation, and consent of the persons whose levels of functioning are being classified. If limitations of an individual's cognitive capacity preclude this involvement, the individual's advocate should be an active participant.
- (4) The information coded using ICF should be viewed as personal information and subject to recognized rules of confidentiality appropriate for the manner in which the data will be used

Clinical use of ICF

- (5) Wherever possible, the clinician should explain to the individual or the individual's advocate the purpose of the use of ICF and invite questions about the appropriateness of using it to classify the person's levels of functioning.
- (6) Wherever possible, the person whose level of functioning is being classified (or the person's advocate) should have the opportunity to participate, and in particular to challenge or affirm the appropriateness of the category being used and the assessment assigned.
- (7) Because the deficit being classified is a result of both a person's health condition and the physical and social context in which the person lives, ICF should be used holistically.

Social use of ICF information

- (8) ICF information should be used, to the greatest extent feasible, with the collaboration of individuals to enhance their choices and their control over their lives.
- (9) ICF information should be used towards the development of social policy and political change that seeks to enhance and support the participation of individuals.
- (10) ICF, and all information derived from its use, should not be employed to deny established rights or otherwise restrict legitimate entitlements to benefits for individuals or groups.
- (11) Individuals classed together under ICF may still differ in many ways. Laws and regulations that refer to ICF classifications should not assume more homogeneity than intended and should ensure that those whose levels of functioning are being classified are considered as individuals.

Source: WHO 2001, pp. 244-5