



THE UNIVERSITY OF
SYDNEY

FROM MEMBERS OF THE CENTRE
FOR DISABILITY RESEARCH AND POLICY
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**SUBMISSION ON THE NATIONAL DISABILITY
INSURANCE SCHEME BILL 2012**

**TO THE SENATE STANDING COMMITTEES ON
COMMUNITY AFFAIRS**

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Authors

Ros Madden
Director, Australian ICF Disability and Rehabilitation Research Program
Stream leader National Disability Insurance Scheme, Centre for Disability Research and Policy
Stream leader Disability and development, Centre for Disability Research and Policy, Faculty of Health Sciences, The University of Sydney

Richard Madden
Professor and Director
National Centre for Classification in Health
Stream leader National Disability Insurance Scheme, Centre for Disability Research and Policy
Faculty of Health Sciences, The University of Sydney

Dinesh Wadiwel
Dr, Director, Master of Human Rights
Lecturer, Socio-Legal Studies and Human Rights
School of Social and Political Sciences
The University of Sydney

Stewart Einfeld
Professor, Mental Health Research Team, Disability and Community Research Group, Faculty of Health Sciences
Stream leader Disability and mental health, Centre for Disability Research and Policy
Head of Laboratory, Developmental Psychiatry, Brain Mind Research Institute, The University of Sydney

Patricia Howlin
Professor of Developmental Disorders, Faculty of Health Sciences, The University of Sydney
Professor of Clinical Child Psychiatry, Institute of Psychiatry, London

Jo Lewis
Discipline specialist, Discipline of Occupational Therapy,
Faculty of Health Sciences, The University of Sydney

Eric Emerson
Professor and Chair in Disability Population Health, Faculty of Health Sciences
Stream leader Disability and disadvantage, Centre for Disability Research and Policy, Faculty of Health Sciences
Professor of Disability and Health Research
University of Lancaster

Luis Salvador-Carulla
Professor in Disability and Mental Health, Faculty of Health Sciences
Stream leader Disability and mental health, Centre for Disability Research and Policy, Faculty of Health Sciences, The University of Sydney

Gerard Goggin
Professor of Media and Communications,
Faculty of Arts and Social Sciences
The University of Sydney

This submission builds on previous submissions made by the co-authors and others: to the Productivity Commission in 2010 and 2011, and to FaHCSIA on 'Eligibility and Reasonable and necessary support' in October 2012 (see References).

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SUMMARY AND INTRODUCTION

The NDIS is an important and needed reform to Australia's disability system. There is much of merit in the NDIS Bill. Its implementation poses some challenges, to ensure a clear, sustainable and rights-based system, resulting in the outcomes desired by the community.

This submission seeks to contribute to the current review of the draft NDIS legislation, and to the design and implementation of the Scheme. We have concentrated on areas where we believe we have something constructive to offer in the timeframe. None of our comments or suggestions implies a need for delay in the Scheme.

Our suggestions are framed in the context of the United Nations Convention on the Rights of Person with Disabilities (CRPD), the technical framework of the International Classification of Functioning Disability and Health (ICF) and an entitlement-based service system which supports people's rights to participate in all areas of life and seeks to provide an environment which enables these rights to be exercised.

Our main suggestions are as follows:

- Section 23: Residence criteria should be based on Medicare criteria, to promote the equity of the NDIS in the wider service system.
- Sections 24, 25, 27: Disability requirements and related rules should be based on an accurate representation of the ICF. Embedding the old linear causal model of disability in the Bill will lead to confusion, inefficiency and challenge. The idea of 'permanent impairment' is not helpful and should be changed. New provisions for these Sections are proposed. Some suggestions about the design of assessment instruments are included.
- Section 26: Our discussion provides some ideas about why and how additional expert reports may assist the process and the person with disability involved. A medical examination should not become routinely sought and nor should a health condition become part of the eligibility criteria.
- Long-term cost containment suggestions are made – including developing models which better estimate the costs of reasonable and necessary supports, as the NDIS matures and experience builds. Such measures are needed, to protect the universality and sustainability of the Scheme.
- Chapter 5 on compensation should be removed and replaced by government-to-government agreements and compensation reforms, to preserve the primacy and universality of the NDIS, and to avoid the costs of adjustment being borne by individual people with disabilities.
- National statistics must be published as part of the Agency's responsibilities and as part of its public accountability for outcomes from the Scheme. As recommended by the Productivity Commission, data should be made available for research. Data should be based on the ICF so that it relates to population survey data and data from other sources based on this international standard. Such data must include information on the environment of people and the service system surrounding the ICF. A critical part of the Australian environment is information and communication

technologies; at present, however, there are shortfalls in access of Australians with disabilities to digital technologies — a 'disability digital divide'. Nationally, we have little precise idea about the scale, scope, and impact of this digital exclusion. This will affect, but can be remedied by, the administration of the Scheme.

- There should be at least 3 people on the NDIS Board with experience or knowledge of the provision or use of disability services (Section 127).
- There are lessons to be learned from international experience, service systems and the wider literature. Implications for the NDIS frameworks, principles and terminology are discussed in our final section.

1. Eligibility and access: Residence requirements

The National Disability Insurance Scheme Bill 2012 provides for residency based restrictions to eligibility for participation in the Scheme.¹ The clause restricts eligibility to individuals who reside in Australia *and* are an Australian citizen, the holder of a permanent visa or a special category visa holder who is a protected SCV (Special Category Visa) holder.

The proposed residency restriction is at odds with Australia's international obligations. Australia has ratified the *Convention on the Rights of Persons with Disabilities* (CRPD). CRPD imposes obligations on Australia with respect to realising the rights of people with disability without discrimination. CRPD provides *no* grounds for discrimination between people with disability on the basis of citizenship or residency. Article 5.1 of CRPD emphasises that "persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law."² Article 5.2 CRPD further emphasises that States Parties will "guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds."³

The proposed restriction on eligibility to NDIS supports for non-residents has particular implications for the treatment of children. Under the proposed eligibility guidelines, persons under 18 years of age who are not recognised as permanent residents will not be eligible for appropriate supports. Excluding non-resident children with disability from supports, including early intervention services, is contrary to Article 3 *Convention on the Rights of the Child*, which places the best interests of the child as a primary consideration. Excluding non-resident children would also be contrary to the obligations imposed by Article 7.1 (and 7.2) CRPD, which emphasises the need for children with disability to enjoy rights on an equal basis with others, and the need for States parties to recognise the best interests of the child

¹ Clause 23 of the proposed Bill states: "Residence requirements

(1) A person meets the residence requirements if the person:

(a) resides in Australia; and

(b) is one of the following:

(i) an Australian citizen;

(ii) the holder of a permanent visa;

(iii) a special category visa holder who is a protected SCV holder; and

(c) satisfies the other requirements in relation to residence that are prescribed by the National Disability Insurance Scheme rules.

(2) In deciding whether or not a person resides in Australia, regard must be had to:

(a) the nature of the accommodation used by the person in Australia; and

(b) the nature and extent of the family relationships the person has in Australia; and

(c) the nature and extent of the person's employment, business or financial ties with Australia; and

(d) the nature and extent of the person's assets located in Australia; and

(e) the frequency and duration of the person's travel outside Australia; and

(f) any other matter relevant to determining whether the person intends to remain permanently in Australia.

(3) Without limiting paragraph (1)(c), National Disability Insurance Scheme rules made for the purposes of that paragraph:

(a) may require that a person reside in a prescribed area of Australia on a

prescribed date or a date in a prescribed period in order to meet the residence requirements; and

(b) may require that a person has resided in a prescribed area for a prescribed period in order to meet the residence requirements; and

(c) may require that a person continue to reside in a prescribed area of Australia in order to meet the residence requirements."

² See Ben Saul. "Advice on the UN Convention on the Rights of Persons with Disabilities." 15 May 2008. Available at: http://www.neda.org.au/files/refugees_and_migrants_with_disability_and_un_crpjuly_2008_final_1.pdf

³ Discrimination against non-nationals is permitted in specific instances under international human rights law. For example, Article 2.3 of the *International Covenant on Economic, Social and Cultural Rights* (ICESCR) provides that: "Developing countries, with due regard to human rights and their national economy, may determine to what extent they would guarantee the economic rights recognized in the present Covenant to non-nationals." As Australia is not a developing nation, it is clear that Article 2.3 ICESCR is not applicable in this case.

as their primary consideration. Similarly, excluding persons with disability under 18 years of age who are not recognised as permanent residents from support services enabling them to participate in education on an equal basis would be contrary to the CRPD obligation in Article 24.2 (c and d), which stresses the need for all children with disability to receive the supports they need in order to attain an effective education.

The proposed eligibility guidelines would exclude asylum seekers from support. Currently the Australian Government offers asylum seekers health and welfare services, (including limited financial assistance, through the Asylum Seeker Assistance Scheme) and temporary eligibility for Medicare.

Legislation underpinning the NDIS must reflect compliance with international law. A practicable revision of the draft legislation, which would offer closer compliance with international obligations, would be to adapt Medicare eligibility conditions as the basis for NDIS residency requirements.

Medicare eligibility is arguably the most directly applicable comparator to the proposed NDIS because of the universal entitlement objectives and coverage of the proposed NDIS.

Currently Medicare offers services to a variety of non-residents including:

- a. some asylum seekers and people granted refugee status;
- b. people who have applied for a permanent resident visa (except for a parent visa) if they have a visa authorising their stay in Australia and have permission to work, or their parent, spouse or child is an Australian citizen or holds an Australian permanent resident visa; and
- c. people who are from a country where Australia has negotiated a reciprocal arrangement that allows for access to Medicare services.⁴

This broader eligibility acknowledges the potential social costs and hardship that would be generated if non-residents – who are nevertheless part of the Australian community – were not able access to essential health services.

The proposed NDIS eligibility requirements fall well short of existing Medicare eligibility. Given the nature of NDIS supports in enabling people with disability to enjoy participation and freedoms on an equal basis with others, it is not clear that restricting eligibility on the basis of residency is justifiable.⁵ We propose that the eligibility arrangements be expanded consistent with the Medicare arrangements to cover all those whose usual residence is Australia.

⁴ See *Health Insurance Act 1973*. Sect 3.

⁵ It is worth noting that the supports that will be provided under the NDIS are not within the realm of economic, social and cultural rights, which may be progressively realised, but immediately realisable obligations that guarantee people with disability the right to participate on an equal basis. Although the *UN Convention on the Rights of Persons with Disabilities* (CRPD) – and other international instruments – in general must guide the development of the NDIS, Article 19 CRPD (particularly 19b) - “Living Independently and Being Included in the Community” – is directly relevant to the supports that will be provided. “Living Independently and Being Included in the Community” is a civil and political right, that guarantees people with disability fundamental human freedoms on an equal basis with others. These rights are “immediately applicable under international law” as per Article 4.2 CRPD. See Kayess, R. and French, P. “Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities.” *Human Rights Law Review*. 8:1 2008.

2. Eligibility and access: Disability requirements

According to Section 21, a person meets the 'access criteria' for the Scheme if they meet age criteria, residence requirements, and either the disability requirements or early intervention requirements (Sections 22-25). The CEO may request assessments or medical, psychiatric or psychological examination (Section 26), and may set rules about the criteria for judging aspects of the disability requirements (Section 27). These sections and their workings are critical to just and equitable administration.

Sections 24 and 25 of the draft legislation set out the 'disability requirements' and 'early intervention requirements' which a person must meet as part of meeting the 'access criteria'.

Recommendation 7.1 of the Productivity Commission report was:

'Working within the International Classification of Functioning, Disability and Health (ICF), the assessment process should identify the supports required to address an individual's reasonable and necessary care and support needs across a broad range of life activities, and should take account of an individual's aspirations and the outcomes they want to achieve.'

Subsequent indications (for instance at meetings and workshops convened by FaHCSIA and the NDIS Transition Agency) have been that the intention is to use the ICF, where appropriate, for conceptualisation of disability. This is a sensible policy. A wide range of experts including people with disability worked throughout the 1990s to create a world standard for definitions and classifications that can be used in policy, service systems and information systems. The ICF can be used to support the UN Convention on the Rights of Persons with Disabilities (CRPD), which has been ratified by Australia. The ICF correlates strongly with the understanding of disability in Article 1 CRPD in its recognition of the role of environmental factors in producing disability.

The ICF

The International Classification of Functioning, Disability and Health (ICF) is the world standard framework for describing, and organising information on, functioning and disability. The ICF integrates the major models of disability. It recognises the role of environmental factors in the creation of disability and the importance of participation as a desired outcome, as well as the relevance of associated health conditions.

In the ICF, functioning and disability are multi-dimensional concepts, relating to:

- the body functions and structures of people (and impairments thereof),
- the activities of people and the life areas in which they participate (and the activity limitations or participation restrictions they experience), and
- the environmental factors which affect these experiences (and whether these are facilitators or barriers).

The ICF conceptualises a person's level of functioning as a dynamic interaction between their health conditions, environmental factors, and personal factors. Disability is thus seen as multidimensional and interactive. All dimensions are important and any one may affect any other. Environmental factors are important, affect everything, must be understood and may need to be changed – that is, reasonable accommodations may be required in a range of environments affecting the person's functioning.

The ICF and applications worldwide are further briefly outlined in *Appendix 1*.

Sections 24 and 27 – and the ICF

The 'disability requirements' of Section 24 fall disappointingly short of the ICF model. In what way? And why does this matter?

The disability requirements (and Section 27) use unnecessary and undefined terms (e.g. physical impairment) and are based on an out-of-date disability model. In particular they refer to 'disability attributable' to various types of impairments – reflecting a linear causative rather than a multidimensional interactive model. The articulation of the section does not take advantage of the standard international model and classification (the ICF) and leaves ambiguity and unnecessary complexity at the heart of the eligibility criteria. Worse, such an approach risks exclusion of people with disabilities whose impairment is hard to pin down (for instance, people with mental health conditions, autism or intellectual disability).

While people may be able to work with and around these criteria, the criteria create risks for the scheme. It is not just that Sections 24, 25, 27 do not use the ICF – it is that, in using an older, rejected, linear model of disability, the Bill flies in the face of evidence about disability creation. It therefore demands (in Section 27) that the administration of the NDIS seek evidence that impairment(s) 'result in' disability when this is not the internationally understood process of disability creation. Such fruitless processes will unnecessarily add to administrative costs and could result in erroneous exclusion of people with disabilities from the Scheme.

It is inefficient and unsatisfactory to attempt to create separate Australian definitions and conceptual structures. The trend is for an increasing number of assessment instruments to be based on or related to the ICF (Mpofu and Oakland 2010). It will be difficult to achieve assessment instruments and processes which are aligned to both the ICF and the NDIS eligibility criteria as currently set out in the Bill. The system will be open to confusion, challenge and appeal.

'Criteria for and decisions about eligibility for long term benefits or care rely on judgment and prediction. A fair system requires relevant criteria, fit-for-purpose measures and evidence based application' (Madden et al 2011). While judgement is required, it should be evidence-informed judgement, in a clarifying framework, about what matters – those aspects of disability and areas of life that matter to the person, and which require support, as provided under the NDIS, to promote the person's social and economic participation.

'Permanence'

The disability requirements also require 'permanent' impairment and support needs, which may nevertheless 'vary in intensity' or be fluctuating or episodic. While it can be understood that the NDIS would not be dealing with short term conditions and support needs, the use of the term 'permanent' is unhelpful, for at least two reasons. First: some health conditions associated with severe disability (e.g., severe depression, psychosis, PTSD) may be very long term, but may not be lifelong; their subsequent absence does not reflect the fluctuations of underlying 'pathology'. Second, we cannot possibly forecast what interventions may become possible in the future, so that requiring sign-off on lifelong prediction may be difficult in many cases. This requirement of 'permanence' could lead to the exclusion of people with

a potentially treatable condition. There is a clear need to target the NDIS at people with longer-term support needs (even if, for some or many, the level of need may be fluctuating). More equity across groups may be achieved with terms such as 'long term' or (as in previous draft material) 'for the foreseeable future' – to be allowed in addition to 'permanence'.

The idea of 'permanence' is also at odds with the NDIS philosophy. There is a contradiction between developing a scheme based on goals and aspirations which implies a complex dynamic system, one aiming to enhance participation, but which also requires 'permanent' disability. The need is to focus on long-term support needs rather than the idea of 'permanent impairment'.

For the Disability Support Pension, two years is the time frame used. A time frame of 5-10 years for the NDIS (possibly as an additional alternative to 'permanence') might be long enough to give recognition that, for most people, change may not occur but, for some people with high needs over a long period, the lifetime level of need cannot be predicted. Then, for instance, the continuation of support needs of someone with, say quadriplegia, may be considered permanent. But in other cases, where it has not been possible to 'sign off' on the idea of permanent, then 'long term' would be recorded and the CEO could then seek more information after 5-10 years, using Section 53.

[The lack of 'permanence' in anyone's situation is in fact recognised in the Bill; Clause 51 requires participants to notify if anything affecting their 'access' has changed; under Clause 53 the CEO can require information if the CEO thinks anything has changed; Sections 47 et seq provide for the review of participants' plans.]

Proposed solution for Section 24

The proposed solution is to base definitions and eligibility criteria directly on the ICF, thereby simplifying the concepts and the wording. All that is required is that a person has a disability and that related support with activities and participation is required.

This is how it could be done ...

Include in the **definitions section**:

- Disability: Disability is a multidimensional experience encompassing impairments, activity imitations and participation restrictions. It denotes the negative aspects of the interaction between an individual (with a health condition) and that individual's environmental and personal factors. (WHO 2001 page 213)
- Impairments are problems in body function or structure (WHO 2001 page 10)
- Activity is the execution of a task or action by an individual (WHO 2001 page 10)
- Participation is involvement in a life situation (WHO 2001 page 10)
- Environmental factors comprise the physical, social and attitudinal environment in which people live and conduct their lives (WHO 2001 page 10)
- Long term disability is a disability which is expected to last at least five years.

Section 24 would then become: A person meets the **disability requirements** if:

1. The person has a disability which:
 - a. based on the best evidence available, is likely to be of lifetime or long-term duration;
 - b. involves activity limitations or participation restrictions in one or more of the following areas: communication; social interactions; learning; mobility; self care; self-management; domestic life; social, community or economic participation; and
 - c. creates support needs which, based on the best evidence available, are likely to be of lifetime or long-term duration.
2. For the purposes of subsection 1, disabilities and support needs of 'lifetime or long-term duration' may vary in intensity over time.

Then:

- Section 25 requires corresponding adjustment
- Section 27 (1) is not needed and should be removed – it may be better to have a general power of the CEO to make rules to support the operation of the Bill than to go into this kind of detail – which here, as has already been explained, reflects an outdated linear causal model of disability, and obliges people to seek evidence on irrelevant matters.

Planning and assessment instruments

To cover the full range of goals that an NDIS participant may have, a broad based assessment instrument would be desirable, covering the full scope of ICF life areas, as described in the Activities and Participation (A&P) chapters of the ICF. The authors of this submission do not consider that any existing single instrument is suitable for this purpose for the NDIS. There is thus the possibility that new instruments need to be developed and tested during the launch phase.

There are two main tasks to undertake when developing a measurement or assessment tool based on the ICF: domain selection; and measurement construct and scale selection.

Domain selection for the NDIS would probably focus on the ICF Activities and Participation (A&P) domains (listed in Appendix 1). There are pointers from previous research that could help in the selection of a parsimonious but meaningful set of domains which nevertheless cover all nine A&P chapters. For instance, the WHODAS 2.0 is a survey instrument developed by the World Health Organization; it is based on the ICF and covers all nine ICF A&P chapters. Kostanjsek et al (2011) propose a generic list of ICF items to examine the impact of health conditions, based on instruments including the WHODAS 2.0 and other research.

Recording and measurement of activity limitations or participation restrictions often focus on constructs such as: difficulty experienced by the person, or assistance required by them (according to research in progress by the co-authors and others). Again there are pointers for these measures – work which can be adapted for use in the NDIS context. 'Difficulty' is the concept underlying the ICF qualifiers which are essentially on a five-point scale (from 'no problem', through mild, moderate and severe, to 'complete' problem). However, for the NDIS, the concept of 'assistance' in each life area is probably more relevant.

A useful possibility for 'assistance' measurement can be drawn from Anderson and Madden's (2011) evidence of the value of simple 'frequency of support needs' questions. These are, essentially: Does not need help/supervision; Sometimes needs help/supervision; Always needs help/supervision or unable to do. Such scaling has been used in the ABS Survey of Disability, Ageing and Carers (SDAC), and has been successfully used in the national disability services collection. In the SDAC the questions are self-report, but in the disability services collection they are used to collect data reported by thousands of service providers and based on records or instruments in use. The same measure is used in the disability data standards included in the National Community Services and National Health Data Dictionaries (e.g. National Community Services Data Committee, 2008) which, for the last category, separate 'always needs help/supervision' from 'unable to do even with assistance'.

The Australian data standards also use the possibility offered in the ICF, of developing additional qualifiers 'such as a qualifier for involvement or subjective satisfaction' (WHO 2001 page 231). The 'satisfaction with participation' qualifier is a summary indicator reflecting the view of the person about his or her own 'involvement in life situations', and incorporates ideas such as choice, control, importance, and the sense of inclusion. It was developed and subjected to consultation and a small amount of testing during the development of the ICF and the national data standards (late 1990s and early 2000s).

Thus the data standards provide two qualifiers each for Activities and Participation, as a means of distinguishing the two concepts, which have separate definitions while being based on the same list of life domains (see Appendix 1).

A related new instrument is undergoing testing at the University; this is not yet a useable instrument, nor is it being proposed for use now. However it is of interest in that it illustrates the workability of an instrument based on the Australian data standards. The tests are enabling further exploration of the concept of 'satisfaction' with participation and its relationship to environmental factors in the person's life. The YIPE (your ideas about participation and environment) is based on the Australian national data standards for functioning and disability based, in turn, on the ICF. The option in the ICF to record environmental factors, and the extent to which they are facilitators or barriers, in relation to each ICF component, is used, to relate relevant environmental factors to the person's satisfaction with participation [WHO 2001:22]. In 2011 and 2012 the YIPE has undergone preliminary testing with small numbers of people with varying disabilities including some associated with stroke and brain injury (e.g. Cheeseman et al in press).

The authors and others are working to combine and further develop these measurement ideas. A well-designed assessment instrument, while distinct from eligibility criteria and outcomes measures, should related closely to their concepts – in the NDIS context, all would focus on participation and support needs.

3. Medical and other examinations

Under Clause 26 (1)(b)(ii) the CEO may request a 'medical, psychiatric or psychological examination'.

Such examinations would need to fit into the overall approach to planning and assessment, and it is therefore worthwhile to note some general characteristics or requirements for assessment under the NDIS.

- A range of professional assessments may be able to contribute beyond those mentioned (i.e. medical, psychiatric, psychological), for instance occupational therapy, speech pathology, etc.
- Assessment methods will need to be standardized to some extent, although different standardized assessments may be relevant for different disabilities.
- Such standardized assessments will need to be of adequate validity
- The results should be translatable to a common structure, including the ICF
- Assessments cannot be too cumbersome and expensive.
- They have to be adequately accessible to all Australian communities.
- The assessment results should be interpretable in cost terms (considered in more detail in Section 4 following).
- The need for any professional training in the use of such assessments requires consideration.
- This could require prioritizing certain interventions in terms of their cost-effectiveness and desirability for the person as all potential interventions may not be affordable.
- A useful model in developing such assessments could be the work of the recent Department of Health and Ageing Expert Working Party on the 3-year-old Health Check.
- The Centre for Disability Research and Policy is developing an approach to NDIS assessment addressing these issues, based on two mental health conditions - autism and schizophrenia - as examples.

Some comments on the assessment of people with autism follow (Box 1), illustrating perhaps some of the factors the CEO could consider when contemplating requesting an additional expert report: how such an assessment could in fact be helpful to the person's case for access and support. The criterion for requesting such an examination should be that the report will help understand the situation of the person and make the assessment better informed. A medical examination should not become routinely sought and nor should a health condition become part of the eligibility criteria.

Box 1: Example of how a person with autism could benefit from an additional report (Section 26)

Individuals with autism can have widely different cognitive abilities across the whole IQ range; they may also have no visible signs of disability. Assessment of need for reasonable and necessary support therefore requires careful consideration.

Functioning is determined less by IQ (which can give a very misleading impression of social competence/daily living skills) and is likely to be highly affected by social and communication (receptive and expressive) difficulties, environmental supports/stressors, and associated conditions (especially anxiety and depression). Individuals who can function well if given high levels of support may break down entirely if this support removed.

Direct interview alone is unlikely to provide a reliable indication of needs because of communication and social problems (individuals are likely to report few difficulties, may overestimate their level of social competence and under-estimate the role of existing care givers).

Behaviour in a formal interview situation can also give an over-favourable impression of competence to an interviewer because this type of setting (structured; one on one; limited social demands) is the type of setting in which individuals with autism are often able to cope relatively well.

In summary, any assessment needs to include information on functioning and life skills in different settings; level of support needed (both formal and informal) and environmental factors that affect ability; and mental health problems. This may require information from other informants as well as individuals with autism (regardless of level of IQ) because of problems in self-awareness and in social and communication skills.

Without such supplementary information or understanding the person may not receive the support they need to function optimally and participate in all life areas.

4. Containing the cost of the NDIS

The additional cost of the NDIS is reported to be around \$8 billion per year. To date, no new revenue source has been identified to finance this amount (as well as the competing but equally necessary additional education finance, the expanded dental access arrangements and aged care reforms).

Possibly more importantly, the existing cost estimates necessarily depend on a range of assumptions. If the costs are in fact higher than currently estimated, there is a real risk of rationing measures being introduced to the NDIS. A likely one is to slow, or worse halt, the roll out of the NDIS, possibly by making specific groups ineligible.

The additional workforce demands that the NDIS will create, and a possible time lag in assessment of the reasonable and necessary support needs of successful applicants, may add to cost pressures to slow the roll out of the NDIS.

The very sensible decision to have a start up process for the NDIS adds urgency to the need to consider and plan for a higher cost than currently estimated. Start up sites will allow trial and comparison of varying approaches and consequent improvement in principles and operations. But an inevitable consequence is advantage for people eligible for the start-up arrangements, compared to others across Australia with similar or greater needs. It is important that benefits in start up sites are not provided at a level that proves unsustainable for the population as a whole.

The method of assessing an entitlement to reasonable and necessary support set out in Section 34 is a 'bottom up' assessment. Such an assessment requires a range of decisions by and about the individual. The quantum of funding depends on the joint outcome of these decisions. In the Bill there is no mention of priority setting among the supports judged reasonable and necessary. It would be anticipated that such discussion would take place as an important element of the planning process, but it should be included in the Bill or the Rules relating to 'reasonable and necessary'.

An apparent tool for ensuring that expenditure for an individual is reasonable and necessary is by use of 'reference packages' of services for people in particular circumstances. It is not known how these reference packages are being developed. The wide variety of factors potentially affecting a person's disability makes their development and relevance

experimental at best. Further refinements of this approach (not just refinement of packages) are an essential element of planning and development for the NDIS and should begin in the launch or initial roll-out phase. This would contribute to cost monitoring and containment, and to preserving equity among individuals with similar needs. Both the ICF and the CRPD would suggest that “reasonable and necessary” supports should aim at enabling social and economic participation for people with disability – this should at least be the guiding principle.

Longer term options for assessing support quantum

The approach discussed above seems inevitable in the launch phase. But given the possible financial risks involved in this approach, it would be prudent to monitor this closely and to start now to develop a possible alternative approach.

We draw attention to the work being done as part of the COAG health reform process, for the introduction of Activity Based funding (ABF) on a national basis, for both in-patient and non-patient (including community) care. The Independent Hospitals Pricing Authority (IHPA) is responsible for setting ‘efficient prices’ for health services.

The University has recently undertaken a consultancy for the IHPA to review assessment instruments for sub-acute care. Sub-acute care includes rehabilitation care. The aim is to use an assessment of functioning to predict the costs of rehabilitation treatment as an in-patient and in the community. The specific outcomes of the consultancy cannot be disclosed by the University. However the use of the ICF as a base for assessment tools was examined in great detail, and the ICF was used as the benchmark for assessment of tools. Once an instrument is selected, Activity Based Funding depends on an analysis of patient costs to determine what combination of patient characteristics (personal data such as age and sex, health conditions and functioning data (contained in the instrument) is best able to predict rehabilitation needs, and so the cost of assistance.

The ABF ideas, applied to the assessment of reasonable and necessary support in the NDIS, would involve the use of participant, health and functioning data to predict the costs of the supports under consideration for NDIS participants. This would not involve arbitrary price setting. Rather, data on participant characteristics and the cost of support assessed using the currently proposed (bottom-up) planning and assessment process would be used to construct a statistical model to estimate the quantum of support to be provided.

It should be noted that

- a. This is not proposing a single ‘score’ to determine entitlement, rather the use of an array of data items within an instrument, to estimate ‘average experience’ within the Scheme for similar participants, for the purpose of comparisons and discussion of what is ‘reasonable and necessary’.
- b. Once the dollar amount is estimated, this can be fed back into the planning and assessment process to inform the discussion of what is ‘reasonable and necessary’. Each of the matters listed in section 34 is worthwhile, and should be considered. This will allow trade-offs to be proposed and considered by a participant, contributing to the setting of priorities by them.

Unpaid care

A particular issue is the assessment required under Section 34(e):

‘the funding or provision of the support takes account of what it is reasonable to expect families, carers, informal networks and the community to provide’

This treats care and support provided by family members and others as part of the ‘environment’ (in ICF terms) surrounding the person with disability who is being assessed. This section could, however, place these unpaid parties in a dilemma, either seeking to maximise funded care or provide a quantum of care that is not sustainable. A conflict between the parties and the assessing agency could result through differing views of possibilities.

Information on the quantum of unpaid care relied on, and the operation of these negotiations, should be gathered from the launch sites. Such information could inform future rules for the operation of this Section.

Scope of NDIS support and interface with other systems

The NDIS, as an entitlement scheme, will be unusual among government support services. The NDIS includes early intervention. This is an excellent provision to mitigate the effects of disability as early as possible in a person’s life. Importantly, early intervention can lead to longer term cost saving for the NDIS by reducing future support needs.

Regrettably other interventions that may have similar beneficial effects, and reduce future costs, appear to be outside the NDIS, and are provided through budget limited systems. Medicare itself is an entitlement scheme, limited in some cases by the absence of an eligible provider (e.g. in some rural areas). But rehabilitation services in hospitals or the community are not entitlement based. In particular, the linkage between hospital based and community based programs is not as well developed as possible, with community rehabilitation being particularly rationed. Yet rehabilitation after disease or injury can substantially reduce long term support costs.

There is no simple solution to this problem, and limited rehabilitation workforce availability means the issue is not just financial. And of course rehabilitation is not the only relevant service that is budget limited: social housing and education are similarly placed.

One possibility is to provide for the NDIS to purchase a range of ‘interventions’ where the NDIS is satisfied that the intervention is likely to reduce support costs in coming years. This would not be an entitlement, but funded by a specific allocation of funds for this purpose.

It is essential that a reverse discrimination not be allowed to develop: this is possible if mainstream service providers were to consider that the NDIS should include provision for purchasing a service that could be available from a mainstream service. It is understood that the Transition Agency is placing emphasis on working with other sectors to establish sensible working relationships, and this approach should be supported.

Transition to work programs are an important part of improving people’s chances of participating in the labour market. Ultimately, this is where the scheme may be able to achieve some social and economic goals, in terms of increased labour force participation.

We know that work is good for people's health (e.g. Waddell & Burton, 2006). To prevent an overlap or doubling up of transition to work services in NDIS and job network providers, there must be clear delineation as to what employment or transition to work services will be funded by the NDIS and what should be referred on to job network providers with appropriate funding through other systems.

5. Discrimination against those with a possible compensation claim

Chapter 5 of the Bill aims to force people with disabilities, who would otherwise be participants in the NDIS, to rely on injury compensation systems, and excludes them from the NDIS wherever possible.

Such an approach is at odds with the concept of the NDIS as a universal entitlement scheme.

However, the approach is consistent with the discriminatory approach taken by the Commonwealth in Medicare and income support benefits. These provisions are also outdated and inequitable. There is no justification to extend bad policy to the NDIS.

Impact on fault based compensation systems on individuals

Chapter 17 of the Productivity Commission report sets out in great detail the compelling case against existing compensation schemes based on fault (PC 2011). The arguments are not repeated in detail here. Major flaws include:

- Uncertainty (chapter 17.4, p798-800)
- The use of lump sums (chapter 17.4, p800-802)
- Delay (chapter 17.4, p802-805)
- Disincentives to rehabilitation (chapter 17.6, p824-826)
- Legal and administrative costs (chapter 17.10, p838-848)

People with support needs would necessarily have to be split into groups, some inside the NDIS, some outside. The process will inevitably be lengthy, invasive and expensive, notably where the determination of fault is contested.

Medical indemnity claims are discussed in chapter 18 (PC 2011, p877-890). All the above problems apply to this area of litigation. In addition, there is the need to prove someone was at fault in the medical accident. Leaving aside the exceptional case of intended harm or criminal negligence (which are appropriately dealt with by the criminal law), a doctor, hospital or other health professional must be 'proved' to have been at fault. Such a process is destructive of reputation and career of the individual or organisation involved. As important, such a process is totally at odds with modern methods of improving health quality and safety which depend on open disclosure and discussion, and are strongly supported by all jurisdictions.

The Productivity Commission specifically recognised the problems of medical indemnity claims for people with cerebral palsy. It recommended that these people be covered by the

NDIS, regardless of any possible compensation claim. The Bill ignores this recommendation, with no explanation.

NDIS should be a national and universal scheme

The NDIS is being implemented on a national basis, through COAG decisions. It is completely against the spirit of a universal entitlement scheme to exclude some otherwise eligible people just because they are covered by a legacy system.

Financing arrangements are being negotiated, with States and Territories making substantial contributions to the finance of the NDIS. If the NDIS removes some liability from a State based scheme, it would be relatively simple to make an adjustment in the financing arrangements between the respective jurisdiction and the Commonwealth to take this into account. (A precedent exists in NSW where there is a transfer of premiums from the third party insurance system to offset the liabilities now covered by the Long Term Care Scheme for people with catastrophic injury.)

In the circumstances, it is unacceptable that the adjustment process should be borne by the individual rather than being resolved between governments.

A much more equitable approach would be:

- a. The States and Territories abolish the common law head of damage for ongoing support, with savings offsetting the cost of NDIS benefits (generally by transfer of savings to the Commonwealth, but for medical indemnity by reduction in existing Commonwealth subsidies).
- b. Negotiate with the States and Territories to remove support provision from their no fault systems (workers compensation and no fault road injury schemes), and transfer resulting savings to the Commonwealth to offset the cost of NDIS benefits.
- c. Remove chapter 5 from the NDIS Bill.

Power to require a compensation claim to be lodged

One particularly contradictory feature, cutting across the fundamental principle of universality, demands special mention. Section 104 provides that if the CEO believes that the participant would be successful in claiming compensation for injuries acquired, then the participant will be given notice to take necessary action to achieve this. However, if the participant chooses not to pursue legal action, or does not conform within the allocated timeframe, then NDIS support will not be provided until the participant takes the necessary action.

This proposal would result in a veto for early intervention services, thereby putting participants at risk of not receiving care they need, and increasing the duration and cost of services. Secondly, it seems inconceivable that government could seek to force someone to take legal action against another person. The NDIS is designed to advance the individual's opportunities to make decisions and take control of their life. A directive for the individual to pursue legal action does not fit well into this foundational concept.

6. Responsibilities for national statistics

Several sections of the Bill relate to the important topic of statistics:

- Clauses 55-68 relate to the provision and protection of information, and deal with privacy
- Clause 172 relates to annual reports and includes:
 - (c) information (including statistics) and analysis that relates to either or both of the following in the period:
 - (i) participants;
 - (ii) funding or provision of supports by the Agency.
- Clause 174 is about reports to the ministerial council and says the data must be broken down by jurisdiction
- Clause 206 includes a power (in subsection 5) to collect data other than for the purposes of the Act.

Taken together these clauses do not meet the expectation that good data, respecting people's privacy, will be made publicly available for public accountability, community information and 'research'. The Productivity Commission Report emphasised this aspect of the NDIS (PC 2011, Chapter 12). The Australian Institute of Health and Welfare Act 1987 deals with a wide range of administrative data; its provisions balance the rights of the person who is the data subject, with the rights and responsibilities of the data custodians, and the rights and needs of the community to have information about the operation of services and the health and welfare of the population. The Bill should say more about this.

The NDIS, as well as the UN Convention, creates the need and opportunity for a national plan to update Australia's national disability statistics. Using consistent data concepts relating to disability, across many service collections as well as the national population surveys, is essential, to monitor outcomes from the UN Convention and the services system generally.

What are required are both population data and NDIS data covering all domains of participation, and environmental factors. The operation of the NDIS, and the data that will be collected through its operations, can add to the valuable data already routinely available through the ABS Survey of Disability, Ageing and Carers (SDAC) and the AIHW's national statistics on disability services (and other collections).

In *Australia's Welfare 2005* the AIHW, after a detailed analysis of participation outcomes from the Survey of Disability, Ageing and Carers, documented some ideas about desirable developments (AIHW 2005 p256). These comments are still relevant and should guide statistical developments related to the NDIS:

Two areas of improvement in the disability survey are desirable: more complete coverage of the 9 ICF domains for activities and participation; and more information 'measuring' activities and participation in these 9 areas. Of the 9 life areas, several, such as self-care, mobility and communication, are covered well and others, such as learning and applying knowledge, are scarcely touched on. Others are mixed with and cannot be disentangled from unrelated ideas; for instance, the 'cognition and emotion' area of the survey includes relationships, feelings and decision making—mixing details from 'interpersonal interactions and relationships' and 'general tasks and demands' in the ICF.

Ideally, to be able to report fully in terms of Australian data standards, it would be possible to report on each of these ICF life areas according to the national data standards (see AIHW 2005b; NCSDC 2004)—that is, for each area, to have data on difficulty and assistance with activities, on the extent of participation in comparison with the rest of the Australian population, and on people's satisfaction with participation.

.....

Finally, there is the considerable challenge of measuring the effect of environmental factors on outcomes.

This last matter – the need to improve data on enabling and disabling environments – is critical for national policy and service monitoring and improvements. This development requires major effort not only in relation to population surveys. Many major services in our society form the environments for people with and without disabilities. To understand their effects, interfaces, quality and outcomes, it is essential that their data are based on common standard concepts relating to the ICF and the national population surveys.

Shared disability items related to ICF are now used in three major national surveys as well as the population census – on health, mental health, and disability, ageing and carers (ABS 2009, 2008, 2009). An analysis combining data from all three surveys reveals the poorer health status and higher exposure to health risks of people with a disability (AIHW 2010) and the economic and social disadvantages experienced by people with disabilities.

Use of NDIS administrative data in national statistics

The NDIS will collect a large amount of data about participants. Data will come from the initial assessment processes, from planning of support services, from services used/purchased by participants, and from outcome measures. Financial data on operations will be collected for accounting and actuarial purposes.

The NDIS needs to publish comprehensive reports and analyses, both statistical and actuarial, using the data it collects. NDIS data will supplement, but not replace, existing data sets. NDIS data necessarily is only available on participants (and to some degree on applicants). Data on the broader population of people with disabilities, and their economic and social situation, must still come from ABS collections. Disability services will for many years have clients who are not NDIS participants.

Statistical data linkage, which does not involve the sharing of identified personal data, is now well established in Australia, and increasingly is conducted across a wide range of data sets, and at national as well as jurisdictional level. Full use should be made of statistical data linkage across all the disability data sets that will now be available.

To achieve meaningful results, statistical data linkage demands the use of consistent data definitions in the various data sets. The National Data Dictionaries provide standard definitions (metadata) for this purpose. It is crucial that the NDIS adopt these standards, and add to them as necessary.

Any lack of correspondence of the NDIS data with the ICF would throw away opportunities to relate reporting and data from the NDIS to other administrative systems and to national population data (Madden et al 2012):

'Major new directions for Australian health and human service systems thus envisage person-centred services, capable of supporting people over time and across different system components. The necessary interconnectedness requires a language for communication among the people, professions and systems concerned, and for interconnected information – a common language about functioning as well as disease. ...

Without functioning being overtly acknowledged and consistently defined, the stage is set for disconnected services, measurements and funding approaches. People with a complex chronic condition should not be expected to coordinate their own care or translate among different professionals – doctors, allied health workers, long term support workers – who use different terms for, and focus on different aspects of, the person's overall goals...

The utility of having population data on demand (or need) and service data on supply based on the same concepts has been illustrated by studies of demand for disability support services.'

We believe the points we made to the Productivity Commission in 2011 remain important (see Box2).

Box 2: Previously submitted comments on national data

In relation to data it is important not to throw the baby out with the bathwater. There are needs to improve data in the disability field, including publicly available data and data for research. Improvements should be made on the hard-won foundations laid over recent decades, features of which include:

- Long-standing national mechanisms for agreeing data standards (Madden et al 2003).
- National data standards, including for disability, agreed by all Australian health and community services administrators (NCSDC 2008), and their value in national statistical collections (Anderson and Madden 2011).
- The presence in the field of an independent statistical body (AIHW), charged with the responsibility of reporting to the Australian Parliament and the Australian people on welfare including disability services, and generally publishing its findings.
- Statistical series created by both ABS and AIHW which have informed policy debates over the last 2-3 decades, the integrity of which must be maintained if trends and longitudinal evaluations are to remain possible.

Source: Ros Madden et al submission DR942 to Productivity Commission 2011

Information and communication technologies: a critical part of the environment

As part of an integrated national plan for consistent, updated disability statistics, the creation of the NDIS via this Bill provides the opportunity to consider a vital, yet neglected issue.

Access to means of communication and information, especially via digital technologies such as media, Internet, and mobiles, are aspects of disability discrimination that governments now need to address to order to ensure compliance with the CRPD. Digital technologies especially are crucial to social participation, and will play a key role in the success of the NDIS — because people with disabilities, their families, friends, and supporters, will gain much of their information in online form. At present, however, there are real shortfalls in access of Australians with disabilities to digital technologies — a genuine 'disability digital

divide'. Nationally, however, we have little precise idea about the scale, scope, and impact of this digital exclusion.

Accordingly, we make three **suggestions** to overcome this gap in policy-relevant data:

- a. There is little information gathered by the Australian Bureau of Statistics on access by people with disabilities to the Internet, mobiles, and computers. Yet this information can easily be sought, and should be — via clear additions to the ABS Household survey and other occasional surveys on digital technologies.
- b. Access and use by people with disabilities of digital media and communication should be gathered as an integral part of the now extensive surveys commissioned by the Australian Communication and Media Authority (who rely on market research firms such as Nielsen to conduct research, so it can be easily modified).
- c. In the information and data the NDIS gathers, the new agency should consider what opportunities it has to gather data (even indicative data) on the access and use of its participants to digital technologies'. It will need such data to plan its own communications with participants.

7. The Board

There is a Chair and 8 other members of the Board

According to Section 127 (2)

A person is eligible for appointment as a Board member only if the Minister is satisfied that the person has skills, experience or knowledge in at least one of the following fields:

- (a) the provision or use of disability services;
- (b) the operation of insurance schemes, compensation schemes or schemes with long-term liabilities;
- (c) financial management;
- (d) corporate governance.

This proposed structure is sound. However it is important that people in category (a) not be a lone voice on the Board. Given the wide range of people who could be eligible for this category, there should be at least 3 people on the Board with the experience or knowledge of the provision or use of disability services.

8. NDIS in the international context

In spite of its novelty NDIS will not develop from scratch. In the last two decades many national schemes for disability have been developed in Europe after the recommendation made by the European Council in 1998. These experiences range from schemes designed for separate care provision for people with disability and older people as in France, to schemes based in different arrays of specific insurance and tax coverage as in Germany, or mainly tax based systems based on ICF for functional dependency in all population groups based on ICF as in Spain. These systems provide useful experiences on the implications of different assessment procedures, of the combination or the separation of health and social care, of the effects of fragmentation or the implications of the economic analysis and monitoring alongside the implementation process.

In comparison to other national schemes NDIS is an advanced system for supporting persons for disabilities. It is universal; comprehensive (as it covers all the population with disabilities, and incorporates in a single schema the whole system: financing, benefits, provision and public policies on promotion); support-based instead of care-based, and aimed at filling 'goals and aspirations' of individuals. It is rights-based, universal, person-centred and oriented to user's aspirations and expectations of their life needs. Other main principles that should be mentioned are Equity and Sustainability.

These characteristics also indicate that the NDIS and the disability system in Australia will be complex and dynamic. Therefore it requires an effective monitoring and evaluation system (as well as the development of a suitable decision system) that may help the policy decision making, priority setting and allocation. It will require a significant effort for designing, feeding and analysing related databases and other information sources.

Other relevant framework components of a disability system which is support-oriented and choice/preference-based are not mentioned in the Bill's 'Principles' statement. For instance:

- Integrated care and continuity of care models. The NDIS document does not provide enough information on this topic. It is important to know whether the system is moving towards integrated care or to other care coordination strategies between the health and the social sector, including the different components of funding and provision related to each sector and the related governance issues.
- Recovery model: In the disability sector, empowerment and shared care agreements are related to the recovery model, and the different recovery care and support strategies related to the recovery model. This is also relevant for the language used in the Bill (e.g. 'permanent disability' may be rephrased under this context).
- Bridging and knowledge transfer approaches: this is another significant area for developing integrated care strategies and to enhance cooperation across different sectors and agencies which may be eventually involved in providing preference-based supports. As the scheme has set an age limit (65 years), the need for a detailed strategy of bridging and knowledge transfer with the ageing sector is even more important in the Australian system than in others such as the US or Spain.
- Information asymmetry models: The development of individual plans based on goals and aspirations would inevitably pivot on the relationship between case-managers (CEO) and users or their nominees to set up individual plans and to allocate funding related the requested/needed resources. The NDIS will be based on contracts and series of decision sets characterised by information asymmetry where one party (Agent) will have more or better information than the other (Principal). The different characteristics of asymmetric models, their implications and the effects that they may have on the development of the NDIS should be acknowledged.
- Equity and parity: The universality of the system should be completed by an approach related not only to horizontal equity but also vertical equity that allows that different 'types/severity/complex' groups of persons with disability receive different packages of care. Parity is a very relevant issue for mental health so users with severe mental illness receive the same support as other groups of persons with disabilities.

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

The International Classification of Functioning, Disability and Health (ICF) is a framework for describing and organising information on functioning and disability. It was approved for use by the World Health Assembly in 2001, after extensive testing across the world involving people with disabilities and people from a range of relevant disciplines.

The ICF integrates the major models of disability. It recognises the role of environmental factors in the creation of disability and the importance of participation as a desired outcome, as well as the relevance of associated health conditions. The ICF 'has been accepted as one of the UN social classifications and...provides an appropriate instrument for the implementation of stated international human rights mandates as well as national legislation' (ICF p. 5-6).

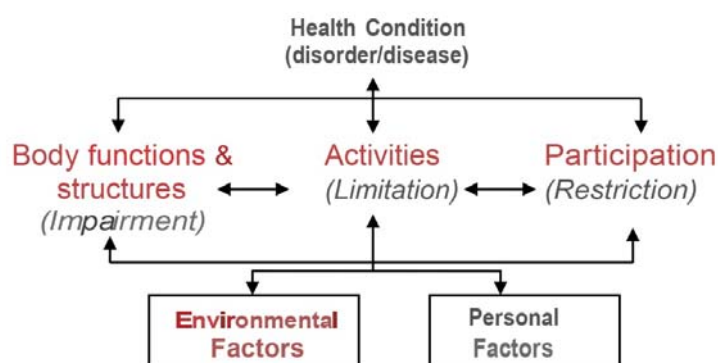
In the ICF, functioning and disability are multi-dimensional concepts, relating to:

- the **body functions and structures** of people (and impairments thereof),
- the **activities** of people and the life areas in which they **participate** (and the activity limitations or participation restrictions they experience), and
- the **environmental factors** which affect these experiences (and whether these are facilitators or barriers).

The ICF conceptualises a person's level of functioning as a dynamic interaction between their health conditions, environmental factors, and personal factors.

Disability is thus seen as multidimensional and interactive. All dimensions are important and any one may affect any other. Environmental factors are important, affect everything, must be understood and may need to be changed.

ICF: Interaction of Concepts



Each component in the ICF is composed of hierarchically arranged domains and categories; The ICF has a separate chapter for each of the domains. The following table lists ICF components and domains.

The ICF is a multipurpose classification system designed to serve various disciplines and sectors across different countries and cultures. People may use the ICF across sectors including health, disability, community care, insurance, social security, employment,

education, economics, social policy and legislation, and environmental design and modification.

ICF Components and domains (Chapters)

Body Function:

Mental functions
 Sensory functions and pain
 Voice and speech functions
 Functions of the cardiovascular, haematological, immunological and respiratory systems
 Functions of the digestive, metabolic, endocrine systems
 Genitourinary and reproductive functions
 Neuromusculoskeletal and movement-related functions
 Functions of the skin and related structures

Activities and Participation

Learning and applying knowledge
 General tasks and demands
 Communication
 Mobility
 Self care
 Domestic life
 Interpersonal interactions and relationships
 Major life areas
 Community, social and civic life

Body Structure:

Structure of the nervous system
 The eye, ear and related structures
 Structures involved in voice and speech
 Structure of the cardiovascular, immunological and respiratory Systems
 Structures related to the digestive, metabolic and endocrine systems
 Structure related to genitourinary and reproductive systems
 Structures related to movement
 Skin and related structures

Environmental Factors

Products and technology
 Natural environment and human-made changes to environment
 Support and relationships
 Attitudes
 Services, systems and policies

The ICF provides a standard language and framework for the description of human functioning, on a continuum - not just at the extremes - and it is important to remember that it classifies functioning, not people. Appropriately collecting functional status information across health and other relevant care systems allows the evaluation of outcomes, comparison of treatments, prediction and management of costs, and assessment of eligibility for government programs.

The ICF is a framework and classification system on which assessment or measurement tools may be based and to which they can be mapped. The broad framework puts assessment in context; it provides the focus for selecting relevant aspects of functioning and disability for assessment.