Submission to the Productivity Commission on Disability Care and Support

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Summary

The authors of this submission welcome:

- the proposal for a scheme to provide long term care and support on an entitlement basis,

- many of the accompanying features of the approach outlined, including the no fault basis of provision, the inclusion of aids and equipment, and the recognition of the need to include the full range of support services,

- the acknowledgment of unmet demand and the need for significant new funding.

1. Who should be eligible?

In this submission we address primarily the issue of eligibility as we consider this fundamental to the design of a long term support scheme. We argue that the framework for eligibility sets the scaffolding for many other considerations such as assessment instruments, qualifications and requirements of assessors, supports and services needed.

Disability and the need for a common framework for policy and information *(1.1)*

Disability is a multidimensional experience, affecting many aspects of life and responded to by a range of supports (technology, formal supports, informal supports, specialist providers, generic providers). Administrative 'definitions' are defined points on a spectrum of infinitely variable human experience; they are intended to communicate eligibility criteria and service descriptors to potential recipients and providers. If person-centred and 'joined up' services are to be delivered, and if we are to build up a coherent understanding of disability nationally, then a universal and relevant conceptual framework and classification is required. The International Classification of Functioning, Disability and Health (ICF) provides such a technical tool, consistent with and capable of supporting the legal, normative framework of the UN Convention on the Rights of Persons with Disabilities ('the Convention'), as well as the National Disability Agreement. The ICF describes functioning and disability in terms of body functions, activities and participation, and recognises the crucial effects of environment as well as health conditions. Australia has instituted the ICF in the Australian data standards for functioning and disability for health and community services, and thus has invested significantly in the ICF as a source of definitions and technical infrastructure for measurement and information. Administrative definitions of disability should be based on ICF concepts.

'Severe or profound disability' is inappropriate as an eligibility criterion for long term support *(1.2 and 1.3)*

'Severe or profound core activity limitation' has been a useful statistical construct for the purpose of summary statistical analysis and trend analyses. It should not be equated to 'severe or profound disability'. It is not applicable in disability policy, eligibility and funding because:

a. It embraces only three of the nine activity/participation domains of the ICF (self care, mobility, communication) and does not align with the UN Convention nor the National Disability Agreement

b. It has no general validity as an eligibility assessment criterion.

c. It does not accord with the profile of current recipients of disability support services, who have important support needs in other areas of life. If used as a primary eligibility criterion for a long term care and support scheme it would create a significant disconnect with current policy and would render many current service recipients ineligible.

Moreover:

- Current disability service recipients have a range of important support needs across all activities and areas of participation and are more likely to need support in areas such as interpersonal relations, learning, work and community life than in self care, mobility and communication. These more common needs of people with disability – including interpersonal relations and domestic life – are very often unmet, as are needs in the area of communication.

- There is no evidence that needs in one area of activities/participation can be used to predict needs in another, in such diverse populations. (That is, needs in the areas of self care, mobility and communication *cannot be used* as indicators of the level of support needed in domestic or community, social and civic life, or interpersonal relationships, work, education or learning.)

Building policy and criteria: Pre-requisites to developing tools for eligibility and assessment *(1.5 and 1.6)*

Clear, non-technical statements about policy and eligibility are pre-requisites to the more technical consideration of eligibility assessment. An ideal development process might follow two broad stages: a plain English statement about the program, purpose and related eligibility criteria; and a process of translating these criteria to assessable eligibility criteria.

Policy, eligibility and principles of assessment

The foundation of the disability support system should be a person centred assessment of the impact of disability on the whole of life of the individual and their family. This could be reviewed at regular points to ensure it takes into account needs, competencies and aspirations – all of which may change across the life span. It is essential that a self-assessment tool be developed, to enable people with disabilities to identify the supports they need in order to fulfil their goals and to participate in society.

Eligibility for long term support should relate to functioning, disability and the need for support. That is, eligibility criteria should go straight to the purpose of the funding,

service or program and the related description of the target group – they should not take a detour via surrogate indicators such as health conditions. Knowing a person's health condition is useful profiling information and may affect the supports needed, but it is not relevant in determining eligibility for long term support. Condition-specific eligibility criteria are highly problematic in a disability scheme.

In this submission, we discuss ways of building on the ideas in the Issues Paper to develop an eligibility statement and relate it to the ICF components. For instance, 'persons in need of significant support' could be interpreted to mean: people needing significant amounts of support (e.g. in terms of time, intensity or frequency), and/or people for whom support would make a significant difference to outcomes in their lives. The quantum and nature of support may be affected by the environment, both the broader service environment and the family environment; however, outcomes for people and for families should not be adversely affected by environmental considerations. This approach can be translated into eligibility criteria drawing on the ICF framework.

For too long, specialist disability services have been framed in a social environment where families are presumed to be, and have been, available to carry out a great deal of the work of support. This can no longer be a default policy option. The UN Convention makes clear the right to participation for persons with disabilities. This right is not contingent on the adequacy or charity of other aspects of the person's environment. In turn, family rights cannot be contingent on the presence or absence of other support for the person with disability.

Wide coverage, allowing 'tailored support to all those who need some services' or support is considered preferable to narrower support targeted to those who need most support. Wide coverage is noted (page 20, Issues Paper) to bear some similarities to the Medicare scheme and this is considered to be a useful parallel. The right to function in daily life and participate in society is embedded in the UN Convention and recognised widely as fundamental to overall health and wellbeing. The UN Convention asserts the right to a life of quality as well as to basic existence; thus, support services as well as acute health services should be universally available.

Evaluating or developing assessment tools

Thinking through the details of policy, eligibility and the processes and principles of assessment creates a clear framework for evaluating the suitability of instruments for assessing eligibility and support needs. Without such clarity, instruments cannot be selected or developed.

It will be important that the Commission recommends building on Australia's commitment to the ICF, on the Australian data standards and the data capture matrix used in the existing data collection (see Appendix). These also provide well-accepted guides for developing tools, and evaluation frameworks for mapping and testing candidate tools.

2. Other comments on key questions

<u>Who gets the power?</u> The proposed scheme should place people with disability at the centre of the delivery system, and empower them to make choices about their individual needs for essential care, support, therapy, assistive devices and aids, equipment, home modifications and access to the community, education, training and leisure activities. This approach need not cost more than reliance on purely professional assessment.

<u>What services are needed?</u> All the types of supports provided in the current array of disability support services are needed, and in greater supply than at present. There should be a forward-looking national policy on and greater supply of equipment and environmental modifications.

A means of interaction with 'mainstream' services is needed, to promote a more universally accessible environment, and to ensure funding in the disability support system is not drained away in compensating for inequities and inadequacies in the provision of generic services such as transport, education and housing.

<u>Funding:</u> The proposed scheme must align with the UN Convention, and contribute to a coherent national policy framework that acknowledges universal rights to health and well-being and includes programs based on these fundamental ideas, like the Medicare scheme and the income support system. Functioning, including full participation, is a right for people with disabilities and their families. Disability support to enable this is no different from other community supports and should be funded in the same way, from tax funds acknowledging community responsibility.

<u>Planning and implementation:</u> People with disabilities, families and NGOs have been significant drivers of innovation and expansion in the field for many years. National management structures should draw more formally on this well of expertise. Other expert members could include allied health practitioners, economic analysts, and research and information specialists able to advise on information design and analysis. Evidence informed plans and implementation studies should be standard practice. The need for more research effort should be funded so as to create a strong, balanced hub-and-spoke model of centres producing a critical mass of integrated, coordinated research.

Submission on Disability Care and Support

Focus of our submission

At the outset it is important to state that the authors of this submission strongly welcome:

- the proposal for a scheme to provide long term care and support on an entitlement basis,

- many of the accompanying features of the approach outlined, including key features such as the no fault basis of provision, the inclusion of aids and equipment, and the recognition of the need to include the full range of support services,

- the acknowledgment of unmet demand and the need for significant new funding.

In this submission we focus mainly on the specific design issue of 'eligibility', with particular reference to the International Classification of Functioning, Disability and Health (ICF).

In our second section we also include brief comments on some of the other 'key questions' posed by the Commission.

1. Who should be eligible?

The terms of reference of the inquiry indicate basic ideas about eligibility and what is to be provided – two clearly related matters:

- The funding and services under consideration are to provide long term care and support, on an entitlement basis, taking into account the desired outcomes of people over a lifetime.

- Eligible people must have 'severe or profound' disability, not acquired as part of 'the natural process of ageing'.

The first point, about what is to be provided, is clear and welcome. This point acknowledges desired outcomes. The UN Convention to which Australia is a signatory provides a legal and normative framework for stating desired outcomes for people with disabilities (as well as the obligations on states for achieving them).

The second point, about eligibility, is conceptually and logically flawed. The concepts of 'severe or profound disability' and 'the natural process of ageing' are not defined. Moreover, as we will outline, they are not easy to define and do not assist in ensuring that long term care and support reach those who need it most.

1.1 Disability and the need for a common framework for policy and information

What is disability?

Functioning and disability can be experienced as effects on any or all of body functions and structures, activities that people do and participation in any area of life. These effects result from the interaction of health conditions with all aspects of a person's environment – physical, social and attitudinal (Figure 1). Functioning and disability are multi-dimensional concepts, relating to:

- the **body functions and structures** of people, and impairments thereof (functioning at the level of the body);

- the **activities** of people (functioning at the level of the individual) and the activity limitations they experience;

- the **participation** or involvement of people in all areas of life, and the participation restrictions they experience (functioning of a person as a member of society); *and*

- the **environmental factors** which affect these experiences (and whether these factors are facilitators or barriers).
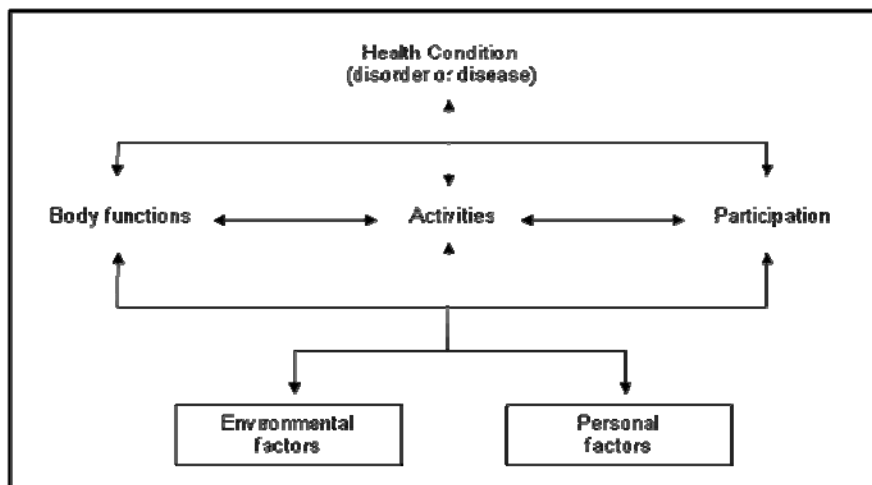

Figure 1: Interactions between the components of ICF (WHO 2001:18)

The International Classification of Functioning, Disability and Health (ICF) provides a standard language and a conceptual basis for the definition and measurement of health and disability, and definitions, classifications and codes for its major components: body functions and structures, activities and participation, and environmental factors (WHO 2001). The aims of the ICF are: to provide a scientific basis for understanding and

2

studying functioning, disability and health, and also changes in health status and functioning; to establish a common language to improve communication between different users, such as health care workers, researchers, policy-makers and the public, including people with disabilities; to permit comparison of data across geographic regions, relevant professional disciplines, relevant services and time; and to provide a systematic coding scheme for information systems (WHO 2001:5). The ICF was adopted as an international standard for these purposes in 2001.

Experts from many different disciplines and countries, including experts with disabilities, were involved in the drafting and testing of the ICF. The framework and the inclusion of environmental factors in the classification have been hailed as an advance by a wide range of writers, from disability advocates to the Lancet (Hurst 2003, The Lancet 2009). Hurst expresses the hope that the ICF framework will inspire policy makers to 'use the environmental factors as a basis for assessing appropriate services, for underpinning non-discrimination legislation, for ensuring appropriate health care and support and that statisticians and epidemiologists will use it for their work'.

The UN Convention on the Rights of Persons with Disabilities, which Australia has ratified, provides a normative legal and moral framework for policy in relation to functioning and disability. The ICF provides a technical framework and detailed language to translate rights, aspirations, policy values and broad aims into workable goals, entitlement programs and related information systems (Madden et al 2010). The quotes in Box 1 illustrate the commonality of approaches used in the inclusive statement of the Convention and the definitions of the ICF. While the Convention stops short of providing a definition of disability, its purpose states a clear obligation to *all* people with disability.

Box 1: Definitions and key concepts of disability

<u>**Article 1 of the UN Convention:**</u>

'The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

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

<u>**The ICF:**</u>

'Functioning … is an interaction or complex relationship between health condition and …environmental and personal factors' (WHO 2001: 19). Components of functioning and disability in the ICF are: Body Function and Structure, and Activities and Participation.

<u>**ICF Australian User Guide:**</u>

'Disability is the umbrella term for any or all of: an impairment of body structure or function, a limitation in activities, or a restriction in participation.' (AIHW 2003:5)

Each ICF component contains hierarchically arranged domains. These are sets of related physiological functions, anatomical structures, actions, tasks, areas of life, and external influences. The ICF has a separate chapter and code list for each of the domains listed in Table 1.

Table 1: ICF components and domains/chapters

Body Function:	Activities and Participation:
Mental functions	Learning and applying knowledge
Sensory functions and pain	General tasks and demands
Voice and speech functions	Communication
Functions of the cardiovascular, haematological, immunological and respiratory systems	Mobility
Functions of the digestive, metabolic, endocrine systems	Self care
Genitourinary and reproductive functions	Domestic life
Neuromusculoskeletal and movement-related functions	Interpersonal interactions and relationships
Functions of the skin and related structures	Major life areas
	Community, social and civic life
Body Structure:	**Environmental Factors:**
Structure of the nervous system	Products and technology
The eye, ear and related structures	Natural environment and human-made changes to environment
Structures involved in voice and speech	Support and relationships
Structure of the cardiovascular, immunological and respiratory Systems	Attitudes
Structures related to the digestive, metabolic and endocrine systems	Services, systems and policies
Structure related to genitourinary and reproductive systems	
Structures related to movement	
Skin and related structures	

Source: WHO 2001: 29-30

The need for a common technical framework for policy design, implementation, information, monitoring and evaluation

Disability affects many people and, according to the ICF, human functioning and disability can be experienced, described and 'measured' on a continuum. **There is no universal dichotomy splitting the population into 'disabled' and 'not disabled' – and, by definition both in the Convention and the ICF, disability varies with environment or context. 'Definitions' of eligibility within particular policy settings are, then, locations or thresholds on this spectrum rather than definitions of disability itself. We cannot continue to be satisfied with an unconnected set of policies, programs and related information; a common technical framework is**

essential, with the ICF the obvious choice, providing underpinning for definition, measurement and statistics.

It is vital to avoid the policy and information problems from the past. The Australian work on the ICF and the related national data standards stemmed at least in part from frustration among policy analysts in the 1990s at the lack of consistency in disability concepts among various administrative approaches. A decade and a half ago the need for consistency was well recognised:

> 'At the centre of many of these national data developments lies an ongoing concern with the basic definitions of disability and disability services. Several major reports have found the planning and evaluation of national programs hampered by the lack of relatability of various data sources (for instance, Senate Standing Committee on Community Affairs 1992; Baume & Kay 1995; Office of Disability 1994). These reports have urged greater consistency in basic definitions, and have recognised the role of the Institute in addressing this pivotal problem.' (AIHW1995: 239*)*

Australia's system for setting national data standards in the health and community services sectors was established to promote consistency in these sectors (Madden et al 2003). The ICF now underpins Australian national data standards for disability, agreed among health and community services administrators. ICF-related national data standards are available on line, comprising a suite of metadata items covering all dimensions and domains of the ICF, and including its qualifiers (NCSDC 2008).

The benefits in using such standards are numerous:

- Efficiency in design effort

- The ability to build a coherent statistical system that provides information about functioning in the population, and in and across different settings, with each source adding to integrated national knowledge

- Eligibility and assessment across major programs could relate more explicitly to national standards and hence to each other and to population data: Improvements here are feasible even within current policy parameters, for instance, eligibility and assessment have been found to relate to any or all of the ICF components both in income support and disability support services (Madden et al 2010) offering the possibility that national data could be made more consistent and hence informative than they are.

- Comparative analyses are enabled: The value of ensuring that population data (indicating need and demand) and program data (on supply) are based on the same concepts has been illustrated by studies of unmet demand for disability support services which have highlighted the need for new funding (e.g. Madden at al 1996; AIHW 2007). International comparisons could also be enabled by this use of the international standard classification.

1.2 Inappropriateness of 'severe or profound disability'

There is a flaw in the Commission's Issues Paper, in that it appears to assume that the ABS statistical construct of 'severe or profound core activity limitation' (needing assistance with self care, mobility and/or communication) has intrinsic conceptual validity as an indicator of 'severe disability'. This is evident from page 7 (Box 1) of the issues paper where the statistical construct is correctly defined but thereafter is referred to as 'severe or profound disability' with a range of implications throughout the paper.

This construct is useful for some statistical analyses at a population level, but was not designed as an eligibility criterion and should not be used for this purpose. This section discusses this construct further, outlining its statistical value, before explaining (in this and the following section) that it does not form a sound basis for eligibility for services, especially for the services needed to achieve the aims of the UN Convention and the National Disability Agreement.

Since 1981, the first year in which the Survey of Disability, Ageing and Carers was conducted, the ABS has endeavoured to ensure that a broad view of disability is taken, and international classification standards are adhered to (for instance, ICF and its predecessor). This broad view generally enables the population survey data to be used for a number of disability-related policy purposes, including statistically relating population data to relevant disability services. Carrying out trend analyses has been facilitated by the construct of 'severe or profound core activity limitation' since the corresponding age- and sex-standardised rates are more stable than those of the survey construct of 'disability' (e.g. AIHW 2005).

Nevertheless, because of the era when the first survey was designed, (a) the 'activities' and areas of assistance considered in the survey bear some resemblance to HACC services in the 1980s; and (b) the statistical construct of 'severe or profound core activity limitation' (needing assistance with self care, mobility or communication) bears some resemblance to the notions of ADL (activities of daily living) often used in the aged care field.

Now, international experts are calling for greater use of the ICF in the aged care field (e.g. Jette 2009) and there are criticisms of the continued use of the ADL models often used in that field. The content validity of the ADL model has been described as 'unclear in complex illnesses where the social context plays a significant role and where symptoms may directly produce a significant impairment of the daily functioning which is not mediated through ADLs' (Salvador-Carulla and Gasca 2010); these authors also suggest use of the ICF.

The authors of this submission do not know of a general measure of 'severity' of disability for use in diverse populations. Further, we do not know of a validated general disability measure that focuses only on self care, mobility and communication, even if such a limited view of disability were to be pursued. Of course the ABS has not, to our knowledge, suggested 'severe or profound core activity limitation' is a general measure of disability severity.

'Severe or profound core activity limitation' has been a useful statistical construct for the purpose of summary statistical analysis and trend analyses. It is not applicable in disability policy eligibility and service determination because:

    d. It embraces only three of the nine activity/participation domains of the ICF, the international standard (see Table 1), and does not align with the UN Convention nor the National Disability Agreement.

    e. It does not accord with the profile of current recipients of disability support services (see following section). If used as a primary eligibility criterion for a long term care and support scheme it would create a significant disconnect with current policy on eligibility and funding/service determination and would render many current service recipients ineligible and no longer receiving services.

1.3 Current recipients of disability support services and funding have high support needs across all areas of Activities and Participation (ICF)

National data about Australia's disability support services and recipients are collated and analysed each year in a National Minimum Data Set comprising 14 questions about service outlets (for instance location, size and service type) and 17 questions about service users. The Data Set was formally agreed by senior administrators in all Australian jurisdictions, which collect data and transmit anonymised data files to the AIHW for annual national collation and publication.

The question about 'support needs' (the need for personal help or supervision) is a 'data capture matrix' comprising rows reflecting the ICF Activities and Participation domains, and columns reflecting the national disability population survey question (see Appendix table for the question and AIHW 2003a for its development). For each of 9 life domains based on the ICF Activities and Participation domains, there are (essentially) three simple categories for the frequency of need for support: needs no help/supervision – with or without aids; sometimes needs help/supervision; always needs help/supervision. This simple two-dimensional data capture framework has useful and desirable statistical qualities, and enables the collection of data from thousands of services using varying assessment methods (Anderson and Madden in press).

Almost one quarter of a million (245,746) people used government funded disability support services in 2007–08 (AIHW 2009); these were predominantly people under age 65 because of the target group of the time. Close to 11,000 outlets delivered services in 2007–08, mainly non-government organizations receiving government funding. Government expenditure on disability support services during 2007–08 was $4.8 billion.

The support needs of recipients were relatively high (Figure 2):

- almost 70% of service users needed support in education, work and/or community life;

- around 70% needed support in interpersonal interactions and relationships; learning, applying knowledge and general tasks and demands; and domestic life;

- some 50% needed support in self care, mobility and/or communication; this compares with 6.3% of people of all ages in the general population who needed assistance with self care, mobility and/or communication in 2003 (ABS 2004).

Of service recipients needing support, almost half needed support 'always' in order to carry out the activity or to participate in that area of life, or else were unable to do so at all.

Figure 2: Frequency of support needed in 9 life areas (grouped): Disability support services recipients 2007-08
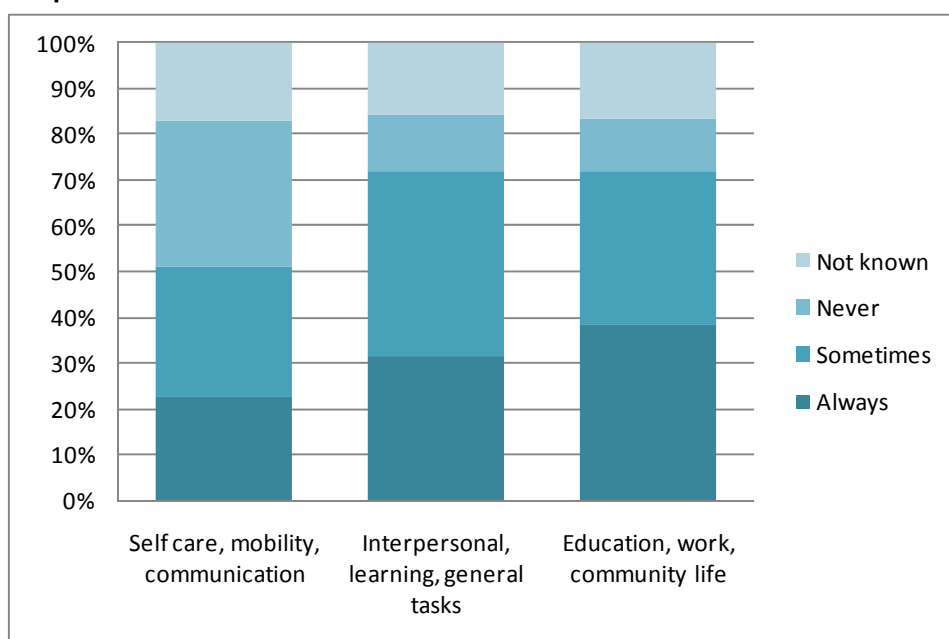
Source: AIHW 2009

Thus we see that:

- **In terms of the three activities on which there is comparative information (self care, mobility and communication) national disability support services are well targeted, with much higher rates of needing support among service recipients than in the general population**

8

- **Current service recipients have a range of important support needs across all areas of Activities and Participation and are in fact more likely to need support in areas such as interpersonal relations, learning, work and community life than in self care, mobility and communication.**

Moreover, from other analyses, we know that:

- **These latter needs – including interpersonal relations and domestic life – are very often unmet, as are needs in the area of communication (AIHW 2005: 255).**

- **There is no evidence that needs in one area of Activities/Participation can be used to predict needs in another, in such diverse populations (Anderson and Madden in press).** That is, needs in the areas of self care, mobility and communication cannot be used as indicators of the level of support needed in domestic or community, social and civic life, or interpersonal relationships, work, education or learning.

1.4 Thoughts on 'the natural process of ageing'

We now turn to the second component of the proposed eligibility criteria. Page 6 of the Issues Paper states:

> 'First, the terms of reference specify that the scheme should cover disability present at birth, or acquired through an accident or health condition, but not due to the natural process of ageing. This means that the size of the relevant group is much smaller than all those with a disability. And, the numbers in this smaller group are projected to grow more slowly than those whose disability is ageing related.'

It is not possible to include a definitive discussion of ageing here. Ageing is often accompanied by multiple comorbidities, health issues, loss of control, shifting roles, functional changes and environmental influences. The ICF framework and definitions equally apply to older people. That is, disability 'due to the natural process of ageing' aligns with the ICF framework and the phrase does not, of itself, provide a distinct category of disability. The ICF, with its full menu of body functions, activities and participation, offers a framework for all ages.

The correlation between disability and age is well known and is illustrated in Figure 3. Disability associated with ageing (by definition) occurs in just one part of the life cycle, but is not distinguished by a separate mechanism of disability creation, i.e. is still related to health conditions and environment (ICF).

There is also a related tendency for certain diseases to be correlated with both age and disability. Such patterns are further complicated because some health conditions commonly associated with age occur earlier for people with disabilities. Comorbidities also complicate the picture of functioning, for instance where there is a pre-existing primary condition (e.g. visual impairment and then age related hearing impairment).

Figure 3: Severe/profound core activity limitation and age: Indigenous and total population
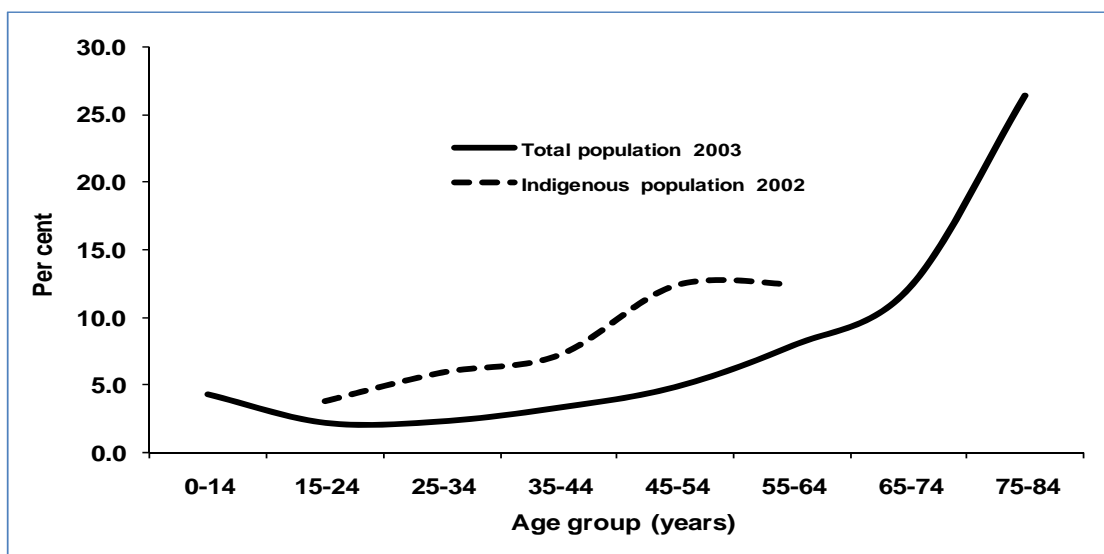
Source: AIHW 2005

There are three options provided in the Issues Paper (page 19) for clarifying this matter for the purposes of eligibility determination: disability acquired before age 65; disability at all ages 'with the exception of certain conditions that are strongly related to ageing and that occur in people after middle age'; disability among people aged less than 65 years. The option of 'providing support for people of all ages, so long as the disability was acquired before age 65 years' may be most practical, being consistent with the current policy. The option of a simple age cut-off at age 65 is generally considered inadequate because of the need to shift people to the aged care system at age 65, when that system may not be flexible enough to deal with people who have experienced lifelong disability. The other option, to select certain conditions that would be considered to represent the 'natural process of ageing' (e.g. dementia or Parkinson's) is considered unworkable – while conditions may be age-related there are many exceptions to the pattern (e.g. AIHW 2004; AIHW 2005). Condition-specific eligibility criteria are highly problematic in a disability scheme. By definition a disability system should focus on functioning and disability, not indirect indicators such as health conditions.

Needs for support, of course, may vary with age, as may the desired activities, participation and life outcomes. One of the advantages of preserving some separation of the disability and aged care systems, for the time being, is that perhaps differences such as life stage, life experiences and resources can be allowed for and the potentially differing needs of both broad age groups can be more clearly recognised and appropriately funded.

In brief, we suggest that it is mainly the stage of the life cycle that distinguishes something that could be called 'disability due to the natural process of ageing'. Having an

10

age-related cut-off is clear although arbitrary; having a health condition 'cut-off' will be unclear as well as arbitrary, and expensive to administer. We then suggest that, of the three options in the Issues Paper, the most practical age-related cut-off mentioned could be the current policy (disability acquired before age 65).

In an ideal system, however, a person might have options to obtain services from the disability support system, the aged care system, or other service systems, depending on what most suited their needs.

1.5 Families and the wider environment

Most people with disabilities live independent, fulfilling and contributing lives. Those who require support receive most of it from families and other informal carers (e.g. AIHW 2007a). As recognized in the National Disability Agreement, carers are people whose rights are also at risk when the formal support system is inadequate. The proposed scheme must therefore focus on both:

- the provision of services related to the needs of people with disabilities, and

- the outcomes for people with disabilities and their families and other informal carers.

While carers and family are an important part of the person's environment, they are all living in a broader environment which affects:

- Each person's functioning and disability and the cost of disability

- Carers' opportunities and costs

- The role, type and level of effort of specialist services.

Disability services are:

- delivered to a person whose immediate environment includes their family and living arrangements, as well as the wider social and service environment;

- influenced by that environment. This is just one reason that local area coordination services (funded under the NDA) take a broad community development approach, and work with the family and community to change the environment in which the person lives, to make it more enabling and lower the day-to-day level of disability.

The environment of the person and any informal carer is, thus, complex and fluid. As is noted in the Commission's issues paper, mainstream services and the wider community affect the level of need for specialist support. Where housing services, transport services, and education systems, for instance, are accessible and inclusive, the need for specialist

intervention is reduced. Policy in these areas should, ideally, improve in clarity and scope as the UN Convention is implemented. The environment is dynamic in that:

- All elements interact with each other, for instance by providing assistance, enabling or inhibiting participation.

- In terms of the assistance the person needs, most elements are both complementary and substitutable – specialist services may substitute for mainstream services, informal family care may fill gaps left by specialist services and vice versa; some people with a disability may 'substitute' for inadequate services by making superhuman efforts to be 'independent' or by enduring limited participation.

- Outcomes for the person and their family take place in and are influenced by all these environmental factors and their interactions.

Local Area Coordination services (now funded in some States under the national disability support services scheme) represent an intervention which attempts to operate in this fluid environment and to form a potential bridge between specialist and mainstream services.

Individual assessment and service planning may need to take into account the aspects of disadvantage which may impact on a person's level of need, such as:

- Socio-economic disadvantage and discrimination
- Capacity to utilise social supports
- Geographic isolation
- The interaction of dual or multiple disabilities
- The presence or absence of an effective early intervention.

While any lack of family or community support should be a factor in assessment, there should be clear limits on the role expected of family members and carers. The right of people with disabilities to move through 'normal' stages of independence from their families should also be respected.

For too long, specialist disability services have been framed in a social environment where families are presumed to be, and have been, available to carry out a great deal of the work of support. For reasons provided elsewhere this can no longer be a default policy option (e.g. AIHW: Jenkins et al 2003; Commonwealth of Australia 2010). The UN Convention makes clear the right to participation for persons with disabilities. This right is not contingent on the adequacy or charity of other aspects of the person's environment. For instance, the inadequacy of support services should not be a bar to a person exercising their right to live as an independent adult away from their parents' home. In turn, families' rights cannot be contingent on the presence or absence of other support for the person with disability.

1.6 Eligibility and assessment: building with the ICF and the Australian data standards

Clear, non-technical statements about policy and eligibility are pre-requisites to the more technical consideration of eligibility assessment. An ideal process might follow two broad stages: a plain English statement about the program, purpose and related eligibility criteria; and a process of translating these criteria to assessable eligibility criteria.

The program, its target group and eligibility criteria – in plain language

A plain language statement has been only partially made for the proposed new program. In the terms of reference what is to be provided is: long term care and support, on an entitlement basis, taking into account the desired outcomes of people over a lifetime. On page 7 of the issues paper it is also stated that:

> '… the scheme is intended for those in significant need of support. These would be mainly drawn from those with severe or profound disability, though an appropriate coverage may include some people with moderate disabilities and exclude some categorised by the ABS as severe or profound.'

The relevance of the ABS construct of 'severe or profound core activity limitation' has already been questioned in this submission and, for the reasons already outlined, it is considered fruitless to seek some relevant or just reason for using it.

Rather, it is of more value to spell out what is meant by 'in significant need of support'. Is a need 'significant' because a large amount of time is needed for support? Because frequent support is needed? Because environmental supports including informal carers are absent or vulnerable? Because support (large or small amounts) might have a significant effect on the person's life?

Depending on the answers to these questions:

- **eligibility could then be described in terms of the frequency and amount of assistance needed in any ICF Activity/Participation domain, and the related outcomes of significance to the person, and**

- **the support provided could be shaped by (but not contingent on) the availability or willingness of an informal carer, the person's own efforts to be 'independent', and the nature of the person's environment (e.g. transport availability, housing availability).**

The need for large amounts of support must surely be a primary criterion as the effects on the person and/or the informal carer of not getting the support can be assumed to be significant. Outcomes are also a key consideration and this is where the environmental interaction must come into play. Environmental factors create complexities for eligibility assessment – just as they do in the lives of people with disabilities. Outcomes for the person and the family may be affected by the quality of mainstream services available – health, transport, education etc – and people should not be penalised for the inadequacy

of such factors; that is, a uniform satisfactory standard of generic services across Australia should not be assumed. Nor should the current ability of an informal carer to provide a great deal of support diminish a person's right to receive adequate support for desired outcomes. **Thus 'persons in need of significant support' could be interpreted to mean: people needing significant amounts of support, and/or people for whom support would make a significant difference to outcomes in their lives. The quantum and nature of support may be affected by the environment, both the broader service environment and the family environment; however, outcomes for people and for families should not be adversely affected by environmental considerations.** For instance, a person's current need for support could be assessed in their current environment (excluding informal care) or in any immediately feasible environment (e.g. if a person were being assessed for the support they would need in a particular location if moving to independent living).

The above approach can be modelled using the ICF framework and the national data standards: the areas of life in which assistance was needed or in which improved outcomes were desired can be identified and qualified; environmental factors can be listed using the ICF and either identified to be facilitators or barriers, and/or included in a profile of the person's needs (e.g. for environmental change). If necessary, 'urgency' of need can be described by either changes in the health conditions or the environmental factors (including carer/s and their availability) – the factors affecting disability in the ICF model.

Wide coverage, allowing 'tailored support to all those who need some services' is considered preferable to narrower support targeted to those who need most support. Small amounts of support may make large differences to people's lives and outcomes, and it is suggested above that this should be one of the criteria for provision of support. Wide coverage is noted (page 20, Issues Paper) to bear some similarities to the Medicare scheme and it is considered this is a useful parallel. The right to function in daily life and participate in society is embedded in the UN Convention and recognised widely as fundamental to overall health and wellbeing (WHO, 2009). To save the lives of premature babies, for instance, and then take no community responsibility for how they and their families live their lives thereafter, is a strange disconnect in policy. The UN Convention asserts the right to a life of quality as well as to basic existence; thus, support services as well as acute health services should be universally available.

Seeking or developing a relevant assessment instrument

Once a plain language description of eligibility and related processes is finalised, then a *relevant* assessment instrument (or set of instruments) can be sought or designed which 'models' closely the main parameters of the policy statement. It will be important that the Commission recommends building on Australia's commitment to the ICF, on the Australian data standards and the data capture matrix used in the existing data collection (see Appendix). The data capture matrix should be used as a template for the information which should remain available, thus providing a further guide for developing tools, and a test for candidate tools.

A number of possible tools are identified in the Issues Paper (pages 26-7) which could be evaluated in this way (although it should be noted that the eFRHOM is a data capture matrix rather than an assessment tool), but there are more. As well as further searching literature, the many agencies now involved in providing services, and others in the field, could be enabled to nominate existing tools with explanations of how they fit existing criteria. A program of work would be needed to evaluate all nominated tools so as to relate them to the new eligibility criteria, the ICF framework and the existing data capture framework; this could ultimately result in rationalisation, for instance the creation of a list of relevant assessment tools (possible for different sub-populations). This process is not to suggest that service providers will determine eligibility but rather that existing knowledge in the field should be assembled. If the results of this search are not entirely satisfactory, a temporary agreement on tools to be used may need to be reached, while further development of assessment instruments takes place.

It is essential that a self-assessment tool be developed, to enable people with disabilities to identify the supports they need in order to fulfil their goals and to participate in society.

The broad goals of the National Disability Agreement are aligned with those of the UN Convention, notably Article 19 asserting the right to live **independently and be included in the community.** Since the new National Disability Agreement no longer describes the target group in terms of just three ICF domains, the way is open to using the full spectrum of activities and participation in devising any new assessment and eligibility criteria; this is imperative in the light of Australia's ratification of the Convention. This approach will ensure relevance to the UN Convention and broad concepts of disability implicit in the National Disability Agreement.

The cost of developing disability assessment tools can be considerable, but applying 'ready made' tools to the wrong measurement question is likely to be more costly. It is important to follow the statistical adage that an exact answer to the wrong question is inferior to an approximate answer to the right question.

Questions on assessment in the Issues Paper

The principles for establishing eligibility criteria for the scheme should:

- Be transparent and based on a nationally consistent assessment process.
- Be person-centred, based on the needs and choices of the person with a disability and their family.
- Take a 'whole of life perspective', focussed on early intervention, long term outcomes and maximising opportunities for participation and productivity. Take account of the gifts and unique attributes of the person with a disability.

Enunciation of such principles enables questions about assessment, such as the following, to be answered consistently and meaningfully.

Some brief comments are included here, to provide additional information in response to some of the questions on assessment on pages 27-28 of the Issues Paper:

- *How should the long-term care and support needs of individuals be assessed?*

  The perspective should be one of proactive planning. The foundation of the disability support system should ideally be a person centred assessment of the impact of disability on the whole of life of the individual and their family. This could be reviewed at regular points to ensure it takes into account changing needs, competencies and aspirations.

  Perhaps the greatest vulnerability of people with disabilities is at transition points, for instance where there is a move from one service system to another. Combined with the sometimes predictable events related to the person's condition, and the different aspirations a person and his/ her carers may have at different life stages, it is clear that planning (with a level of certainty about the availability of resources) can avoid much of the trauma and dislocation of transition.

  Assessment should be grounded in these principles and should use well-tested scientific tools which support this philosophy. As has been outlined previously, the ICF provides infrastructure for this.

- *What are the appropriate features of assessment tools?*

  The usual psychometric and statistical criteria for such tools should be met, such as validity and reliability across individuals and several disciplines. The tool also needs to make sense to people and families and be tested for use as a self-report tool.

- *Should assessment gauge both eligibility and the extent of need in the one set of instruments, or should the assessments be distinct?*

  The assessment should be done in the one process even if more than one instrument is needed. (However this will depend on whether a register is created (see section 2.4), possibly requiring an initial assessment.)

- *Should a nationally consistent tool be used (and what process would be used to achieve consistency quickly)?*

  There should be a nationally consistent process and this may require a nationally consistent tool(s). However there will be a transition period (for a range of arrangements under the new scheme) even if such a tool were ready now. This period can be used to refine and bed down new assessment arrangements. Once the plain English version of eligibility is agreed, the survey of existing tools can be done fairly quickly, but further developments can also be scheduled. For instance it could be possible to start new clients (from Date A) with the new criteria and a

suite of existing tools relevant to these criteria, but proceed to develop a purpose built national tool. This tool could then be used for new clients from a certain date (Date B), for pre-existing clients from existing schemes (before Date A) and in any ongoing reviews of clients (including clients brought into the schemes between Dates A and B). A self-assessment tool could be tested with people already receiving individualised funding, with their agreement

- *What are the risks associated with different approaches and how can these be minimized?*

  The greatest risk in the area of assessment is the speedy adoption of an irrelevant instrument; the financial costs could be considerable, and later re-direction of such a large program very difficult for a range of reasons. That is why this submission advocates the two-stage development process outlined in this section. (Again, it is useful to remember the old statistical adage: that an approximate answer to the right question is better information than a precise answer to the wrong question.)

- *Who should use assessment tools (GPs, specialist disability staff, specialists)? Who should employ or engage the assessors?*

  The need for support is best understood by the person concerned and they must be integral to the assessment process. More needs to be known about the comparison of self report and professional report on this topic; the apparent statistical stability of self reported data on assistance needed, in the ABS population survey, is an indicator that self reported data are of value. Aspects of functioning and disability are often assessed by allied health professionals, working with the person and family. Medical practitioners need only be involved if a diagnosis is to be recorded in the person's record or a general health check provided as part of the assessment process; this is worthy of consideration.

- *How would the accuracy of assessments and the performance of assessors be gauged?* 'Accuracy' relates to validity and reliability of the tool. If the tool meets these criteria then assessments and assessors can be judged for consistency with each other. In some fields, standard practice is certification of assessors to use particular instruments. A testing and monitoring process could be developed; there is probably relevant experience in the social security field to inform this. Such standards also need to be national, to establish national eligibility i.e. interstate transferability.

  Published statistics and relevant data will also be crucial in monitoring the trends in assessment and the related factors including eligibility data. Data to be collected would include functioning and disability as measured, support needs, health

conditions, environmental factors, goals and outcomes as well as supports received, and demographic factors.

- *On what basis should beneficiaries be reassessed? How should assessment processes take account of changes in life circumstances?*

Changes in any of the eligibility criteria – including environmental factors – could require re-assessment.

However, as stated above, the perspective should be one of proactive and holistic planning rather than periodic re-assessment. Assessment could be reviewed at regular points to ensure it takes into account changing needs, competencies and aspirations.

- *How would data from assessment be used? (For example, should it be available to a range of service providers?)*

A personal record could be created as proposed for electronic health records, to be used, with the person's permission, by a range of providers. Statistical data – a new MDS – should also be created with results made publicly available.

It is important for the proposed scheme to simplify the assessment processes and consider mechanisms by which information can be shared (with relevant consent). A more integrated service system would ensure that any comprehensive or specialist assessments required would build on, rather than repeat, information collected at other levels of assessment. An integrated information management system could be established relating to all recipients of the scheme, proving information about the level of need and required level of support to authorised people. Such an information system could reduce delays in providing services, reduce duplication of effort and wasteful resources, and reduce unnecessary intrusion into people's lives.

2. Other comments on key questions

This second section of our submission comments briefly on a selection of other matters raised in the Commission's issues paper.

2.1 Who gets the power?

The proposed scheme should place people with disability at the centre of the funding and delivery system, and empower them to make choices about their individual needs for essential care, support, therapy, assistive devices and aids, equipment, home modifications and access to the community, education, training and leisure activities.

Individualised, self directed funding is clearly an important option to be used increasingly in the system. The Issues Paper is right to identify factors that need to be weighed up in the early years of growth of this option. There are solid reviews of literature in the field and good expertise in the field in Australia and we do not propose to comment further on this issue (see for instance the submission of In Control Australia).

Giving people responsibility for planning and identification of priorities for expenditure is not only an ethical principle in line with modern health and disability policy, it can also save money. For instance:

> 'The New Zealand Accident Compensation Corporation funds medical, rehabilitation and disability costs for people who sustain a severe injury (moderate to severe brain injury, spinal cord injury or comparable injury) on a life long, no fault basis. In 2007 the National Serious Injury Service was established to deliver a sustainable rate of growth in liabilities and improve client outcomes. Application of the ICF model with its distinctions between impairment and activity and its concept of participation as impeded or facilitated by the environment, alongside the contemporary disability practice of person-centred planning, was used to frame case management, assessment, service decisions and design. The use of these complementary approaches has resulted in a significant reduction in the rate of growth and improved client outcomes.' Maree Dyson pers. comm.

That giving people more control over their funding need not cost more is also evidenced by experience from Sweden, where direct payments were introduced for personal assistance through the Swedish Independent Living Movement over two decades ago and replicated in other countries since that time.

2.2 What services are needed?

On page 25 of the issues paper it is stated that:

> 'the core formal services required for a well functioning disability care and support system are usually grouped into personal care services, respite and accommodation services, community access, community support, income support, employment, transport, aids and appliances, home modification, but also a range of intangible services, such as counselling and mentoring.'

It is worth noting that:

- The current system also includes (under 'community support') services such as local area coordination which sometimes may focus not just on one individual but also on environmental change of immediate benefit to people more generally.

- Significant change is required to increase the range and adequacy of supply of equipment. There has been a shortage identified since before the mid 90s when Professor Anna Yeatman coordinated a review of national disability support services. The lack of national policy and adequate supply will become increasing issues as technology is brought to bear on a range of human functioning difficulties.

- 'Home modification' may be too narrow a focus. While modifications in work places, schools, tertiary education institutions, transport systems, etc may not be the responsibility of disability support services, there has to be some link or overarching plan that ensures that people are not isolated in a support system which is itself isolated in the broader service system.

The Issues Paper rightly notes that different approaches may be required for Indigenous Australians; again, only consultative development can establish suitable approaches. What is certain is that much greater resources need to be available, as disability rates among Aboriginal and Torres Straits Islander peoples are some 2.4 times the rate of other Australians (AIHW 2006; ABS &AIHW 2005)

Overall, in a person centred system, the services provided should be flexible and portable, and reflect the individual needs and preferences of people with disabilities and their families. The system should not be limited to a specific set of service types, but seek to respond flexibly to the funding of solutions assessed as effective to meet the needs of eligible people. The proposed scheme should:

- Provide mechanisms which identify the person's needs as early in life as possible to ensure that supports are in place to allow people with disabilities to live within their community from the outset
- Be easy to navigate by reducing the number of professionals with whom people with disabilities need to engage
- Have clear referral pathways and equitable access to a range of services

- Provide choice and flexibility, in particular when a service is considered inappropriate
- Provide consistent services across the country to allow people with disabilities to move if their circumstances change.

2.3 Funding and administration

So as to align with the UN Convention, the proposed scheme should be based on a rights philosophy that recognises that functioning, including full participation, is a right for people with disabilities and their families. This fills a current policy gap. Moreover, it contributes to a coherent national policy framework that acknowledges universal rights to health and well-being, and includes programs based on these fundamental ideas, such as the Medicare scheme and the income support system.

Funding for such schemes is then seen as a community responsibility, met through the taxation system. Taxpayers would need to have demonstrated to them the benefits and offsets for this expenditure, including: better services, better quality of life for thousands of people, lower risks of hardship, no need for difficult or expensive litigation in the case of unanticipated injury and disability, and the release of a currently not available workforce in both people with disabilities and their families. Disability support, however, is no different from other community supports and should be funded in the same way.

It is hard to imagine a service array that does not involve many of the existing NGO service providers, many of whom have been pioneers in the field. They have evolved in recent years as the purchaser-provider model has become more prevalent in the disability services field and again, more recently, as trials of individualised funding have been undertaken in Australia.

2.4 Organising and implementing a new disability policy

The issues paper raises the question of advisory boards as a mechanism by which stakeholders have a 'say' in the proposed scheme. This involvement is essential.

People with disabilities, families and NGOs have been significant drivers of innovation and expansion in the field (AIHW 1993). National management structures should draw more formally on this well of expertise.

Other expert members could include allied health practitioners, and research and information specialists able to advise on information design and analysis.

The roles of such a board could include to:

- advise on the initial development of the proposed long term care and support system, including the design features outlined in the issues paper and here;
- promote integration with other services
- promote NDA goals including:

- adequate, equitable and consistent access to services across the country

- adequate and consistent service quality, in terms of outcomes for people with disabilities and carers

- develop and oversight a collaborative process to enable development and sharing of data, and use of data to improve outcomes for people and quality of services and,

- advise on the longer term development of the long term care and support system.

Transition and growth

Strong growth is envisaged, assuming the Disability Investment Group estimates are in the right ballpark:

- New clients will be joining the system as eligibility is established.

- Growth in services and the workforce is required; related supply side issues may further add to costs, for instance the need to pay service providers appropriately.

- Growth in funds is also required.

The transition to a new system will require careful planning – it cannot all happen overnight. This simultaneous growth and transition could be woven into a plan – allowing growth over perhaps 5 years, with the above issues being addressed, for instance (respectively) by:

- Creating a register of people requiring services as is done in Scandinavian countries. (Waiting times and unmet need could more routinely be estimated.) Entry into the register could be based on self-assessment.

- Planning to 'grow' services and workforce, adjusted as knowledge from the register came on stream.

- Increasing available funds, the quantum also able to be adjusted by improved information from the register.

Workforce strategy

For people with a disability and their families it is the qualities and expertise of staff which are of greatest concern – and their ability to deliver the supports needed by the person in an appropriate way. For service providers it is their capacity to attract and maintain such staff, and to provide an environment conducive to quality outcomes for the person. A comprehensive workforce strategy is required, if the quality of the service system is to be enhanced. Such a strategy will have many elements – including, as noted in the consultations of the organisation Spinal Talk, 'better pay, better qualifications'.

Data collection and research

On page 40 of the Issues Paper, responsibility for data coordination is raised. Australia has much admired national data coordination structures, namely the Information Agreements in the health, housing and community services sectors, anchored by the work of the AIHW, operating under its legislation. The establishment of Health Workforce Australia and the Australian Health Practitioner Regulation Agency are two other examples of national commitment to coordination and publication of information relevant to the health and wellbeing of all Australians. Areas of the current system that work well should be harnessed by the new system, and encouraged by the new governance structures to improve and to support the new system.

Clearly all bodies with a role in administration and delivery of services will have a role in data collection and should be involved in data design; a properly constituted advisory board, as outlined above, will have a critical role in information design and analysis. A national commitment to coordination and publication of information represents an important underpinning of quality and accountability.

There is a need for an injection of funds into disability research in Australia, to improve the evidence and information available to the field and to policy makers. This should be designed to create a critical mass of research in various centres around the country, integrated and coordinated nationally. The submission of the Australian Human Rights Commission supports the idea of an Australian National Disability Research Institute, as recommended by the Disability Investment Group. We suggest that a strong, balanced hub and spoke model would work most effectively, with a small 'Institute' playing a coordinating role, fostering the development of centres of research excellence in the field.

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Appendix table: Question on frequency of need for support (AIHW 2009a)

11. How often does the service user need personal **help** or

supervision with **activities** or **participation** in the following life areas?

Please indicate the level of help or supervision required for each life area (rows a–i) by ticking only one level of help or supervision (columns 1–5).

The person can undertake activities or participate in this life area with this level of personal help or supervision (or would require this level of help or supervision if the person currently helping were not available)	1) Unable to do or always needs help/supervision in this life area	2) Sometimes needs help/ supervision in this life area	3) Does not need help/supervision in this life area but uses aids or equipment	4) Does not need help/supervision in this life area and does not use aids or equipment	5) Not applicable
LIFE AREA					
a) Self-care e.g. washing oneself, dressing, eating, toileting	☐1	☐2	☐3	☐4	■
b) Mobility e.g. moving around the home and/or moving around away from home (including using public transport or driving a motor vehicle), getting in or out of bed or a chair	☐1	☐2	☐3	☐4	■
c) Communication e.g. making oneself understood, in own native language or preferred method of communication if applicable, and understanding others	☐1	☐2	☐3	☐4	■
d) Interpersonal interactions and relationships e.g. actions and behaviours that an individual does to make and keep friends and relationships, behaving within accepted limits, coping with feelings and emotions	☐1	☐2	☐3	☐4	■

NOTE: *In the following questions* **'not applicable'** *is a valid response* **only if** *the person is* **0–4** *years old.*

	1)	2)	3)	4)	5)
e) Learning, applying knowledge and general tasks and demands e.g. understanding new ideas, remembering, problem solving, decision making, paying attention, undertaking single or multiple tasks, carrying out daily routine	☐1	☐2	☐3	☐4	☐5
f) Education e.g. the actions, behaviours and tasks an individual performs at school, college, or any educational setting	☐1	☐2	☐3	☐4	☐5
g) Community (civic) and economic life e.g. recreation and leisure, religion and spirituality, human rights, political life and citizenship, economic life such as handling money	☐1	☐2	☐3	☐4	☐5

NOTE: *In the following questions* **'not applicable'** *is a valid response* **only if** *the person is* **0–14** *years old.*

	1)	2)	3)	4)	5)
h) Domestic life e.g. organising meals, cleaning, disposing of garbage, housekeeping, shopping, cooking, home maintenance	☐1	☐2	☐3	☐4	☐5
i) Working e.g. actions, behaviours and tasks to obtain and retain paid employment	☐1	☐2	☐3	☐4	☐5