

## **NDIS Feedback: Eligibility and reasonable and necessary support**

This response is from the **Australasian Society for Intellectual Disability**. The mission of the Australasian Society for Intellectual Disability is to improve the quality of life for people with an intellectual disability. The Society is an independent authority on intellectual disability issues across Australasia, which aims to forge interaction between intellectual disability research, policy and practice.

### **Issues re Eligibility**

Question 1). Does this description of eligibility cover all the things that you think a National Disability Insurance Scheme would need to know about how to determine whether you should be eligible to receive support under an NDIS?

### **Response**

- In Part 4 b the terms **‘substantially reduced functional capacity’ and ‘activities of daily living’ should be more clearly defined** to ensure that they are consistently interpreted. They are drawn from the conceptual framework of the World Health Organisation’s International Classification of Functioning (ICF) which defines them broadly and as being multi-faceted. We suggest reference to this document would be beneficial in providing a deeper understanding of these concepts for community members<sup>1</sup>.
- It is very important from the perspective of people with intellectual disability that **‘activities of daily living’ include the domains of socialisation (interpersonal interactions and relationship), communication, mobility, decision making, and self direction/self-management**, – this is not made clear in the proposed definition or the examples given in the text. The need for a definition of restrictions that includes self direction was clearly discussed in the Productivity Commission report and various submissions made to those consultations. Unless the expression “activities of daily living” is defined broadly, it could exclude a very high proportion of people with intellectual disability.

The Productivity Commission considered the situation of people with intellectual disability and concluded that approximately 40% of individuals with intellectual disability do not face a

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<sup>1</sup> See for example <http://apps.who.int/classifications/icfbrowser/> . We note too that the recent AIHW report on Disability services uses the classification of Daily Living ; Activities of independent living; Activities of work, education and community living.

“core activity limitation” (a limitation in self-care, mobility or communication) but may have a lower capacity to participate in society than people who do have such limitations. People with intellectual disability face special challenges in learning and applying knowledge, forming social relationships and in decision-making. This includes identifying and choosing options at key life transition points and adjusting to changed circumstances and unfamiliar environments, maintaining relationships and interacting with others.

The Commission’s proposed eligibility definition did not focus on activities of daily living. Rather, it required that an individual have “significantly reduced functioning in self-care, communication, mobility or self-management and require significant ongoing support”. The term self-management was included in response to the above challenges facing people with intellectual disability. Self-management includes being in control of one’s behaviour, insight, memory and decision-making.

We see it as very important that the NDIS funding be available for the needs of people with intellectual disability who may be independent in many respects but need support in areas such as healthy lifestyles, building and maintaining social relationships or personal crises, financial management, avoiding and responding to exploitation, caring for children or maintaining tenancies. The proposed focus on activities of daily living: will exclude from the NDIS a very high proportion of people with intellectual disability; leading to a narrow focus in the kinds of supports that can be funded under the NDIS.

- In part 4 c it is not clear why participation in the community and employment are singled out as the only two possible domains of participation that are likely to be affected by impairment. We suggest **that other domains should be included and wording such as ‘participation in one or more life domains**, such as; social relationships, use of community facilities, use of public transport, engagement in leisure and social activities, employment or participation in the community. The other option is to leave just two high level domains but be clearer about the different element that fall with the concept of participation in the community.
- **Part 3 should include autism spectrum disorder.** As it stands individuals with high functioning ASD have a disability that is permanent and that substantially reduces their participation in the community or employment. However with appropriate supports, they have the potential to participate in the community and employment and to reduce their dependence on families. In spite of their significant challenges that often prevent their participation in society, many would be ineligible for support

from the NDIS according to the proposed eligibility criteria. Around 60 percent of individuals with ASD who fall into the high functioning group (IQ greater than 70), are likely to be ineligible. It is therefore proposed that the eligibility criteria be amended to include autism spectrum disorder and read as follows:

*The individual has a disability that is attributable to an intellectual, psychiatric, cognitive, neurological, sensory impairment, autism spectrum disorder or a combination of impairments; or is a child with a global developmental delay;*

- It would be very useful to spell out why and how the definition to be used varies from other definitions of eligibility for disability services used in Australia, and to reference where the definition to be used by NDIS is to be found in the literature. For example it is difficult to understand why the relevant part of the definition in the 2006 Victorian Disability Act was not used.
- Once a definition is adopted it would be useful if it were adopted consistently in all jurisdictions in disability legislation and policy.
- **Part 5 of the definition is most problematic and our view is this should be omitted as it is much more clearly relevant to decisions about what type of support is to be funded rather than eligibility.** A decision about ‘not more appropriately met by other systems...’ requires a judgement that must take into account context which will vary across and within jurisdictions. It will be exceedingly difficult to reach this type of judgement without a full appraisal of each person’s situation, which is why we feel it should be left as part of decision making about what is to be funded i.e., what are reasonable and necessary supports for a particular individual? The definition of reasonable and necessary supports appears to duplicate what is included in section 5 of the eligibility criteria.
- If section 5 were to be included a clear statement is needed about how it should be interpreted, because currently it **could mean: needs ‘can possibly be met’ by other systems (if resources were available or services were adapted) or ‘should be met’ by other systems (but are not necessarily being met) or are ‘actually being met’ by other systems or are demonstrably likely to be met, and this is consistent across all jurisdictions).** We note that a similar type of open statement is used in the <sup>2</sup>social security legislation (regarding a continuing inability to work), and

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<sup>2</sup> Social Security Act 1991

is misleading as to whether it means, 'is unable to work' or 'is unable to find work' because there are no opportunities or due to discrimination etc.

- We do not think that 'foreseeable future' needs to be included in this section, as this is covered in the discussion around 'permanent disability' on page 3.

Question 2. Are there additional questions that an NDIS should ask people before deciding if they are eligible to receive support?

- We acknowledge that the definition of eligibility must come before details of procedures, however, ASID believe that the **process for assessment and the qualifications of assessors will be central to implementation of the eligibility criteria**. We are particularly interested in the process of assessment, the evidence to be used and the qualifications of assessors. Different assessment process should be used for different ages or stages of life course of applicants, it cannot be a one size fits all, and skills and knowledge of assessors will have to reflect the different types of impairment applicants will have. A person skilled in assessment of neurological impairment for example will not have the skills necessary to assess a person with intellectual disability. We note the experience in regard to assessment procedures for disability support pension where there has been a progressive decline in the expertise and qualifications of those making assessments, which has shifted from highly qualified professionals to para professionals.
- It is not clear whether any acknowledgement will be made that some people are already in receipt of disability services and may not be eligible under the proposed criteria.

### **Reasonable and Necessary Support**

- As suggested above we think that Point 5 of the eligibility criteria could be omitted as this is dealt with under Point f of the definition of reasonable and necessary. The issues that arise in considering this are those mentioned above. That is, a clear statement is needed about the meaning of 'more appropriately provided through other systems'. Currently, this **could mean: needs 'can possibly be met' by other systems (if resources were available or services were adapted) or 'should be met' by other systems (but are not necessarily being met) or are 'actually being met' by other systems or are demonstrably likely to be met, and this is consistent across all jurisdictions**).

- **In our view the suggested elements a – e are value based statements which have both subjective and objective components. These may more usefully be regarded as the factors to be taken into account and weighed up in decision making, rather than each being regarded separately.** In this way a decision would investigate and weigh up all elements to reach a conclusion. This is similar to the way decisions are reached about concepts such as ‘a marriage like relationships’ in the social security legislation .
- **Point c, ‘Are effective and evidence informed’** illustrates the subjective and value based nature of these elements. It gives the impression there is an objective test to be met. However there is a remarkably small evidence base to some areas of disability services and, further, little evidence-based practice. ‘Evidence informed’ is a much looser concept and leaves open judgements about how robust the evidence needs to be. The levels and types of evidence required needs further explanation. Who will judge the evidence as satisfactory, or possibly unsatisfactory, for the intervention? Where does the person’s preferences, experience and judgement figure in decisions made? This is particularly relevant if the collected ‘evidence’ suggests that the person prefers a particular type of support. **We suggest that the terms ‘reasonable and necessary’ should be grounded in three layers of evidence, that from research, practice experience of practitioners, and about the person’s preferences.**
- **Judgements about all of these criteria are not black and white; there are many shades of grey that reflect culture, location, preferences and the situation of each individual person with a disability.** For some people, purchasing the services of a prostitute is ‘reasonable and necessary’ for their quality of life, for others this may be abhorrent. For some people, going to the football may be ‘reasonable and necessary’, yet for others, this is completely unnecessary for their quality of life.
- **Community expectations are too difficult to capture as a criteria. There is no one community in Australia; there are many reflecting different values, expectations and so on. Research and experience suggests that many people and even disability support staff hold fairly conservative expectations** regarding community

inclusion of people with severe and profound intellectual disability <sup>3</sup>. **Should these low expectations be taken as ‘community expectations’** when pilot and demonstration projects, and some families have demonstrated outcomes that far exceed ‘the’ communities low expectations?

- Value for money will depend on values, preferences and culture.
- Individual goals are likewise subject to many different interpretations. Are aspirational goals to be included in this process?
- **There is no consideration of the different ways in which ‘reasonable and necessary’ may be determined for a child compared to an adult. Family-centred approaches are widely accepted as best practice in work with children and their families, and therefore the needs of the family as a unit must be included in determining ‘reasonable and necessary’ supports for children.**
- We suggest these points a-f should be reframed as a set of principles to guide the decision-making process about what is ‘reasonable and necessary’, rather than used as objective criteria. **Of central importance is that what is judged as ‘reasonable and necessary’ reflects the individual’s lifestyle choice, research evidence and practitioner experience and wisdom.**

We note that the document in general is difficult to follow, and language changes throughout. For example, on page 3 there is reference to severe functional limitation and on p 4 reduced functional capacity. It is unclear if the the document is focussed solely on Tier 3 eligibility or whether Tier 2 is included in the discussion. If both Tiers are included then the distinction between the two needs to be much more clearly articulated.

We note that all the examples relate to physical support needs, and there are no examples of the need for less visible support needs, such as with self direction or decision making. This is a major problem given that one of the biggest groups of current disability service users are people with intellectual disability, and this is likely to be replicated in the NDIS.

Overall, ASID believes that the proposed NDIS eligibility definition and process of assessment need to be clearer, especially in relation to taking account of the particular needs

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<sup>3</sup>Bigby, C., Clement, T., Mansell, J., Beadle-Brown, J. (2009). ‘It’s pretty hard with our ones, they can’t talk, the more able bodied can participate’: Staff attitudes about the applicability of disability policies to people with severe and profound intellectual disabilities. *Journal of Intellectual Disability Research* 54, 4, 363-376

of people with intellectual disability. Unless the needs of people with intellectual disability are included in the definition and process, we fear that the NDIS may fail to benefit a large proportion of the most vulnerable people in Australia.

Further details about this submission can be obtained from Richard O' Loughlin, ASID president Richard O'Loughlin ([richardoloughlin@bigpond.com](mailto:richardoloughlin@bigpond.com)) or Professor Christine Bigby, ([c.bigby@latrobe.edu.au](mailto:c.bigby@latrobe.edu.au))