



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

A response to the Select Council

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1. About the eligibility description

1.1 For people with a disability

The Select Council seem to have made an error in its proposed definition of eligibility. The definition focuses on activities of daily living and substantially reduced functional capacity. (4b) This definition risks excluding those recommended for inclusion in the final Productivity Commission Report – that is, people who need support with ‘self management’.

- Some people with less severe forms of intellectual disability, with psychiatric disability, acquired brain injury or autism spectrum disorder may not have substantially reduced functional capacity in self care, mobility or communication (ADL’s). They may nevertheless have self management difficulties including learning difficulties, limitations to independent decision making, financial or household management and limitations to interactional or relationship difficulties-that is limitations to their Instrumental Activities of Daily Living (IADLs).
- While the definition acknowledges the inclusion of individuals with impairments in relation to participation in the community or employment (4c) we are unclear how this will be defined. Is it Activities of Work, Education and Community Living? (AWECs)? Is that definition inclusive of limitations in IADL’s?
- We are pleased at the inclusion of people with a psychiatric disability and suggest that ‘impairments of a chronic or episodic nature which result in the need for ongoing and long term support’ may be a better definition. Some adjustment is required to achieve consistency and alignment between the eligibility criterion of an impairment being “permanent or likely to be permanent” (eligibility 4a) and the strong national mental health policy commitment to recovery focussed approaches to treating and supporting people with a psychiatric disability¹. This is not only an issue of ideology. Receiving a formal assessment that one is likely to experience schizophrenia for the rest of one’s life has the potential to run counter to efforts to engage with rehabilitation activities or access other supports. Sensitive medical practitioners and health professionals are loathe to make such predictions about permanence even when clinically equipped to do so. This could create an inequitable barrier to access to an NDIS for people with a psychiatric disability.

It may be envisaged that individual assessments about the permanence of a person’s condition will not be deemed to be necessary, rather that certain conditions are listed as being likely to be permanent. However, this approach runs the risk of reverting to a diagnostic based eligibility system rather than one that centres around a person’s level of functioning and support need. For this reason, Carers Victoria recommends that eligibility criterion 4a. is reworked to refer to the impairment being “long term or likely to be long term”, accompanied with guidelines clarifying the duration of ‘long term’. Eligibility No. 5., “the support needs will persist for the foreseeable future” creates fewer problems.

- We also support the inclusion in 3 of ‘a child with a global developmental delay’. This can both:
 - Ensure access to early intervention support when diagnoses are unconfirmed.
 - Avoid premature disability labels.

Carers Victoria recommends that the draft eligibility statement:

- **Explicitly includes assessment of a person's functioning and needs in relation to Instrumental Activities of Daily Living in addition to the more narrow Activities of Daily Living**
- **Replaces the criterion that an impairment is "permanent or likely to be permanent" with "long term or likely to be long term".**

1.2 For caring families and friends

Carers Victoria expected the NDIS to operate under a critical principle that eligibility for care and support applies to people with a disability and, where applicable, their caring families. That is, it would be both person centred and family focused. We note that:

- Interdependence with family is the reality of the lived experience of most people with a disability and their families. In 2003, 97.5% of people with severe and profound limitations who were under 65 lived in the community. Of these, 84% of people with severe and profound limitations lived with family; 10% lived alone, and 3.2% lived with unrelated people, probably friends².
- There is increasing evidence about the negative impacts of caring for some (high needs) carers. The costs to carer health and well being can be high; rates of anxiety and depression are high; financial security and social connectedness can be severely compromised³.
- There is increasing evidence that inadequate support for people with a disability and their caring families can result in costly crises and unplanned interventions. The Victorian Equal Opportunity and Human Rights Commission (2012)⁴ estimated that 50 children with a disability each year enter Victorian state care:
 - Relinquishment of children with a disability to the care of the state is a consequence of:
 - Unmet need for support, particularly facility based respite, in-home support or behaviour management support;
 - The absence of protocols to identify at risk families and the lack of capacity and funds for early and preventive intervention.
 - This results in:
 - Considerable trauma and harm to children, their parents and siblings and frequent moving of the child between alternative care arrangements.
 - Family breakdown both before and after 'relinquishment.'
 - Unplanned and inefficient financial burdens on the disability system:
 - It costs 4 times more to place a child in a disability respite service than to provide intensive respite 2 days per week, or shared care.
 - It costs 7 times as much to place a child in out of home care than to provide intensive respite 2 days per week⁵.
- While there is limited national data and limited research concerning the relinquishment of adults into care outside the family home:
 - It is known that some may be relinquished into respite facilities or Emergency Departments.
 - Research in one state identified that 32 adults were relinquished into respite care in another state⁶ (Nankervis et al 2009)

- The annual report of the Office of the Public Advocates Community Visitors (2010)⁷ identifies the issue of respite beds being blocked by ‘relinquished’ adults.
- Predictors of a family’s need for support are complex and diverse but include:
 - Characteristics of the individual such as onset of adolescence, high need for behavioural support; significant intellectual disability; some people with autism spectrum disorder, people with high care needs due to multiple disabilities and people requiring extensive support during periods of acute psychiatric illness.
 - Family characteristics –such as significant financial pressures or disability costs; stress, isolation and limited informal support; sole parents (usually mothers) with several children with a disability or a very challenging child; multiple intergenerational care situations; young, at risk children with significant care responsibilities; older parents and parents with disabilities or serious illness.
 - The support context – any limited availability or accessibility of needed services and supports such as coordination and planning, behavioural support, supportive educational settings, or respite support. This needs to acknowledge the impact of withdrawal of formal and informal supports and family needs for support with lifecycle transitions.
- Family needs are unlikely to be static. Transitions and/or changes in the circumstances of the person needing care or other family members can affect the level and type of support needed. Examples of changes include those pertaining to: health status, workforce participation, household makeup, or indeed changes to eligibility rules for other support programs.

What this means for eligibility for NDIS

Eligibility for NDIS must, in some cases, extend to allow a consistent, preventive and early intervention response to the needs of a caring family, including the funding of adequate planned and regular respite, in home support, and behaviour management support.

Carers Victoria recommends that the draft eligibility statement includes the following:

Families of people with a disability are in scope to receive support funded under an NDIS based on:

- ***A purposeful and structured conversation with caring families being an essential part of the eligibility assessment process. This can be based on Carers Victoria's model⁸ or a similar tool which explores how the needs of the family carer and the person with a disability can be equally assessed and considered, including consideration of the sustainability of informal care. It is a means of considering the support services needed by both. In addition it provides a means of exploring differences in the needs, priorities and aspirations of the family carer(s) and those of the person with a disability. Differences can be acknowledged and negotiated within the needs assessment and funding allocation process.***
- ***Consideration of known predictable indicators of risk (above) and***
- ***The allocation of a funded support package as required ensuring that family care is sustainable and the expectations of families are based on what can reasonably and willingly be provided.***

2. Reasonable and necessary support

The Select Council's working description of 'reasonable and necessary' supports:

- Is highly individualised and omits consideration of the person in their family situation and the inclusion of family supports as outlined above. A person and family centred approach will more accurately reflect the lived experience of most people with a disability.
 - The proportion of families needing support may be comparatively small, although the current services system does not have a ready means of monitoring or quantifying family support needs.
 - Any efforts to improve the disability system must be inclusive of the needs of some families for support to sustain care at home. To allow the very high costs of some informal care situations to continue would represent poor scheme design on the grounds of both effectiveness and morality.
 - The capacity of the Commonwealth Respite and Carelink Centres to provide intensive family intervention and support or regular respite for high needs families is very limited.
- For many people with a lifelong decision making disability, it is impossible to determine 'reasonable and necessary' supports without involving their families;
 - In consideration of their support needs.
 - In consideration of the changing needs of the family at transition points.
 - To assess the capability, willingness and costs to family members of providing care.
- Carers Victoria has observed for some years the policy divide between the disability rights movement and the carer movement and the resulting competition for limited resources⁹.
 - For some time there has been a policy emphasis on the rights of people with a disability to maximise their potential, to live independently in the community, to

participate equally as citizens in employment, social life and community affairs - with adequate support according to their needs. We thoroughly support this view.

- But people with a disability are diverse. Such a policy emphasis has difficulty in addressing the practical application of participation and citizenship for adults whose disability is such that they are not self determining and cannot make major daily life decisions. In these situations the support and assistance of family is crucial to making choices about services and in life plans.
- The proposition that adequate support for the person with a disability provides support for and a respite effect for their families can be true for some families but is not always the whole story. High needs, at risk families also need direct support to sustain their role in providing the major proportion of care and support to the person with a disability. They need early intervention and preventive support when crises occur in the circumstances of the family or the person with a disability. They too need opportunities to participate in community life and employment. There is potential for Australia to lead the way in the development of a person centred and family focused disability services system through the NDIS.

Community Expectations

- Carers Victoria has serious concerns about the role and application of community expectations in determining what is reasonable to expect from families and carers. We note that any guiding community norms need to be clearly stated for consistency in interpretation, but this will be a complex task. Community norms are largely underdeveloped and rarely discussed in relation to some people with a disability and their families. Different community norms may apply to different care situations. For example, spousal care in old age may be viewed within the community as to be expected, provided the negative impacts of this are not too high. On the other hand, community attitudes may be more polarised and contested when it comes to the notion of children caring for others. Furthermore:
 - While it is generally expected that parents undertake the care and support of their children, some children with a disability have care needs that are beyond what is normative, reasonable or sustainable for their families.
 - There are no clear community expectations about what is reasonable to expect from families of adults with lifelong decision making disabilities. i.e.
 - Most adults with significant decision making disabilities do not reach the standard markers of adulthood – drivers license, leaving home, establishing a career, living independently, marriage and offspring
 - The current experiences of their families are outside community norms. Community norms have difficulty in addressing the practical application of participation and citizenship for adults whose disability is such that they are not self determining and cannot make major daily life decisions. The support and assistance of their family is crucial to their choices about services and in life plans.
 - A lack of resources has meant that these individuals characteristically don't leave the family home until their parent(s) dies or can no longer care¹⁰.
 - For some people with significant decision making disabilities, it is impossible for them to conceive of a life outside the family home.

- There has been little policy or practice attention to the importance of family relationships for people with a disability or to understanding the positive roles of caring families of adults with significant decision making disabilities. These have key implications in terms of responsibility and support in decision making, representation, supporting package management, futures planning and in relation to the need for partnerships with services providers. Yet the informal advocacy and decision making support role of families of adults with significant decision making disabilities:
 - May not be accepted by services providers on the grounds of 'adult rights'
 - Is not supported by enabling mechanisms that formally support their representation of the needs of their son or daughter to risk-averse banks and other financial institutions, landlords, power companies and the like.
 - Is not reflected in mechanisms which support families in formalising ongoing representation plans for their son or daughter when they can no longer care.
- General community norms for Australian adults may emphasise the right to choices and opportunities in employment, study, community and family participation. These need to apply equally to caring families. For example:
 - Carers should be acknowledged as individuals with their own needs within and beyond caring, and
 - Carers should be supported to achieve greater economic wellbeing and sustainability and where appropriate should have opportunities to participate in employment and education.¹¹
- The notion of community norms should not be used exclusively to determine the level of care family or other unpaid carers should provide. Families are extremely diverse in their capacities and willingness to provide and receive care. These characteristics, circumstances and attitudes cannot be determined without personal contact with the person with a disability and their family members. An assumed level of family care provision, unagreed, could unintentionally cause harm and may be in breach of human rights frameworks¹² by mandating unpaid work and removing the choice of family carers to participate in the paid workforce.

In short, community norms are not sufficient to reliably determine a reasonable level of carer support and should not be a substitute for inclusive family assessment processes.

Carers Victoria recommends that the Select Council's working description of 'reasonable and necessary support' is modified as follows.

Reasonable and necessary supports are:

a) Designed to support the individual and where appropriate their family to achieve their goals and maximise their independence.

b) Support the individual's capacity to undertake activities of daily living to enable them and their families to participate in family, community and civic life and employment.

c) Effective and evidence informed

d) Value for money

e) Based on explicit community norms while recognising and compensating for the non normative lived experiences of many people with a disability and their families, identifying risk indicators and making decisions about what is reasonable, necessary and sustainable for caring families on an individual basis.

f) Determined through whole of family assessment processes in which the needs, wants and aspirations of the person with a disability and those caring for them are taken into account.

References

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³ Carers Australia (2011) Ensuring a good life for people with a disability and their families. Submission to the Productivity Commission Inquiry into disability care and support, May 2011; Cummins et al (2007) Special Report, the wellbeing of Australians; carer health and wellbeing, Deakin University; Gill et al (2007) The health and wellbeing of adult family carers in South Australia; Edwards et al (2008) The nature and impact of caring for family members with a disability in Australia, AIFS.

⁴ VEO&HRC (2012) Desperate Measures: the relinquishment of children with a disability into state care in Victoria.

⁵ Ibid

⁴ Nankervis, K et al. (2009) why do families relinquish care? an investigation into factors that lead to relinquishment into out of home respite care. Journal of policy and practice in intellectual disability.

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¹⁰ Kroehn, Hutson, Faulkner and Beer (2007) the housing careers of persons with a disability and family members...AHURI

¹¹ National Carer Recognition Act (2010) 'Statement for Australian Carers'.

¹² International Covenant on Economic, Social and Cultural Rights