National
disabilityinsurance
Scheme

EC15-000331

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Independent Advisory Council

23 July 2015

The Hon Mal Brough MP
Chair
Parliamentary Joint Standing Committee on the
  National Disability Insurance Scheme
Parliament House
CANBERRA ACT 2600

Dear Mr Brough

The purpose of this letter is to provide you with advice prepared by the Independent Advisory Council (IAC) in late 2014 and early 2015 for the National Disability Insurance Agency (NDIA) Board.

Section 144 of the *National Disability Insurance Scheme Act 2013* (NDIS Act) outlines the function of the IAC to provide advice to the Board about the way in which the NDIA carries out its functions. The advice has also been provided to the COAG Disability Reform Council as per section 145 of the NDIS Act.

As the advice is relevant to the deliberations of the Committee, I have attached it for your information. The advice considers reasonable and necessary supports and mental health.

On reasonable and necessary, the advice considers reasonable and necessary supports in the context of the participant lifespan, families, planning, independence and self-management.

On mental health, the IAC consulted affected people, family, carers, advocates, the mental health sector and trial sites to better understand how the NDIA responds to applicants with mental health issues. The advice provides recommendations for improving the Scheme's responsiveness to people with disabilities related to mental illness.

Enclosed is the NDIA's response to the advice. It outlines the actions the NDIA is currently taking, as well as future planned work, which will address the IAC's recommendations.
A detailed work plan is also being developed, against which the NDIA's progress will be monitored. The NDIA will report to the Board and the IAC on its progress.

Please do not hesitate to contact me if you have questions on the attached IAC advice.

Yours sincerely

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Reasonable and Necessary Support across the Lifespan: An Ordinary Life for People with Disability

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Appendices

A. Reasonable and necessary support across the lifespan

Executive Summary

The National Disability Insurance Scheme (NDIS; the Scheme) has been established to provide 'reasonable and necessary supports' to individuals with a severe and permanent disability.

'Reasonable and necessary support' refers to the nature and quantum of support to enable a participant to pursue goals and aspirations. It must give effect to Australia's obligations under the United Nations Convention on the Rights of Persons with a Disability (UNCRPD) by supporting people with disability to live independently and be included in the community, to develop their capacities and to enable them to exercise choice and control. Reasonable and necessary support must also be value for money, effective and beneficial for the participant, while taking into account what is reasonable to expect families, carers, informal networks and the community to provide and be most appropriately funded by the NDIS rather than through other government systems of service delivery.

The paper takes an 'ordinary life' in 21st century multicultural Australia as its starting point because people with disability share the ordinary aspirations of their peers without disability but need reasonable and necessary NDIS support to achieve them. The ordinary life provides clues as to how these aspirations would typically be met providing a useful benchmark to guide understanding of reasonable and necessary support.

It is hoped that this document is used:

- by the NDIA in its ongoing development of the Scheme
- by participants in conceptualising their goals and aspirations
- as part of conversations with mainstream service providers about assisting people with disability to achieve an ordinary life, and
- as an educational tool for the broader Australian community on the role and purpose of the NDIS.

In reading this paper, the reader should be aware that core to the NDIS are the insurance principles and scheme sustainability. This means that in providing reasonable and necessary supports, the National Disability Insurance Agency (NDIA; the Agency) takes a long-term investment approach, noting that early intervention and other support can increase functioning, independence, and economic and community participation. The NDIS is only one part of a broader disability system that requires systemic changes to ensure the NDIS can flourish. The provision of 'reasonable and necessary support' will by itself transform the lives of people with disability. It requires community involvement, the removal of structural barriers to economic and community participation, the provision of services by mainstream providers and the development of a deep and robust market, which will only develop with time.

Accordingly, this paper acknowledges that the successful implementation of some of the recommendations contained in this paper depend on the broader disability reform agenda, including the National Disability Strategy.

Section 2 draws on evidence from the fields of psychology, education and work, and in relation to ageing, to explore factors that improve health and wellbeing in an ordinary life. These factors are described as enablers of an ordinary life because evidence confirms that they contribute to quality of life by meeting fundamental human needs. The factors include:

- positive relationships
- a sense of belonging
- individual autonomy
- active involvement in decision-making
- active engagement in community
- using one's unique strengths in ways that provide a challenge, and
- making a contribution.

To date, the capped crisis driven state disability service systems have enabled people with disability to aspire to a service. By contrast, the NDIS enables people to aspire to a life, and pursuit of the enablers is the best possible opportunity to 'get a life'.

Section 3 examines significant barriers to an ordinary life, such as:

- negative attitudes that view disability as a tragedy, and people with disability as eternal, dependent clients
- service models that congregate people and segregate them from community
- individualised support that acts as a paid friend rather than as a life facilitator, and
- risk management approaches that deprive people of ordinary opportunities.

The paper outlines ways by which the NDIS can better support an ordinary life. In particular, the paper considers the benefits of providing quality infrastructure to underpin direct support and enhancing arrangements to purchase staff training. The paper notes that without such measures, direct support often remains as a paid friend rather than a facilitator of relationships, making it difficult for participants to pursue their own interests and develop informal support.

The paper also considers the need for the NDIA to continue to develop the Scheme so that supports can be used innovatively and in a cost effective manner.

The importance of capacity building for people with disability and families is noted, recognising its role as a major stimulant for change in the disability service provision market. Capacity building will ensure that 'demand' is created, to which the market must adapt. While the Independent Advisory Council (the Council) accepts that the market will need to evolve over time and is largely outside the control of the NDIA, any strategy to develop the market, and expenditure of sector development funding, should focus on capacity building.

Sections 4, 5 and 6 canvass additional considerations related to people who experience multiple disadvantages, i.e. Aboriginal and Torres Strait Islanders (ATSI), people of culturally and linguistically diverse backgrounds (CALD) and people living in rural and remote areas, and identify additional work that is required. The paper highlights the need to undertake further work in these areas as a matter of priority.

Section 7 examines what reasonable and necessary support would look like for cohorts of people with disability and the families with whom they live.

Section 8 encourages the NDIA to consider how it could think about consciously working towards the enablers of an ordinary life.

Recommendations

In relation to reasonable and necessary support:

1. <u>Consider how the concept of ‘an ordinary life’ can be captured in guidance materials for planners and participants on what constitutes ‘reasonable and necessary support’</u>

Research identifies clear factors that contribute to health and wellbeing, namely positive relationships, a sense of belonging, achieving autonomy, active involvement in decision-making, opportunities for challenge and contribution. These factors are described as the enablers of an ordinary life but are not currently given prominence in NDIS material, either for participants or planners. This is primarily because the *National Disability Insurance Scheme Act 2013* (NDIS Act) requires the NDIA to provide reasonable and necessary supports that are aligned to individual goals and aspirations.

The Council recommends that the Agency considers how an ‘ordinary life’, consistent with the objectives and principles of the NDIS Act could be used to guide what is reasonable and necessary support.

2. <u>Re-organise information about reasonable and necessary support in ways that promote the enablers of an ordinary life</u>

The document *Support Clusters Definitions and Pricing* provides information primarily for planners and service providers about services and supports. The Council considers that this information could be organised in a way that highlights the features of an ordinary life, while still being consistent with the NDIS Act. Accordingly, the Council recommends that:

a) There is an audit of guidelines on supports and consideration given to how these could be framed to enable participants to have an ordinary life.
b) The information provided about services and supports (the current *Support Cluster Definitions and Pricing* document) is reorganised for the purpose of highlighting life tasks and supports to build an ordinary life.
c) The process of reframing information about supports is co-designed with people with disability, families, advocacy and capacity building organisations, service providers and the NDIA.
d) Steps are taken to gain greater consistency in supports provided in a plan, especially access to support coordination to implement a plan.

3. Operationalise the recommendations in relation to an ordinary life across the lifespan

Appendix A has used the lifespan approach to provide guidance as to what reasonable and necessary means across the lifespan.

The Council recommends that the NDIA consider how it could operationalise this as guidance for planners, participants and the general community.

In relation to Scheme design:

4. Consider the strategies to enhance the capacity of participants to direct their own support

If direct support is to transform an outing with a paid friend to the facilitation of relationships, build informal support and then fade out paid support, quality plan implementation support is required to provide an infrastructure. This is also required if participants want to begin to take on responsibility for staffing or support coordination. In an insurance framework, this is an important upfront investment that will lead to improved and more sustainable outcomes for participants.

The Council recommends that quality plan implementation support required to provide life building support for an ordinary life is considered an essential element of reasonable and necessary support.

5. Ensure opportunity for participants to select their own staff

The capacity to select one's staff is an aspect of self-direction most valued by participants and essential if participants are to develop valued roles and informal support.

The Council recommends that the NDIA consider how participants could be encouraged and supported to select their own staff, instead of relying on service providers to act on their behalf.

6. Enable participants to purchase training in specific skill sets for staff

Many participants want their staff to have core skills that are not provided in any standardised training. Other participants actively seek staff that have never had disability experience because they want to orient and train staff in specific skills fundamental to their work.

The Council recommends that in developing the workforce strategy, and in undertaking further work on the efficient price, that consideration be given to how targeted training can be provided to staff that require a specific understanding or skill in order to meet the support needs of a participant.

7. Make provision for life planning as part of reasonable and necessary support

Through its community roundtables, the Council has found that participants want changes in their lives but currently struggle to articulate what they want and how they will achieve it. They need time and support to plan over an extended period. Elsewhere, the Council has recommended that the NDIA, while still applying the NDIS Act, differentiate in practical terms between a funding plan and a life plan: a funding plan being the quantum of NDIS funds allocated to provide reasonable and necessary supports; a life plan being the plan for a participant to achieve their goals and aspirations.

The Council recommends that every participant should be provided with access to support for life planning, the results of which will be submitted to the NDIA for consideration as a plan—noting that to accord with the NDIS Act, the NDIA would need to ensure that the supports aligned with the participants' goals and aspirations.

8. <u>Consider innovative ways that supports can be provided, including through home share arrangements</u>

The Council recommends that the NDIA consider innovative ways of enabling support to be provided. For example, the Council recognises existing practice whereby people with disability encourage individuals without disability to live with them and provide informal supports in return for subsidised rent.

While the Council supports this approach, it notes that it is always the responsibility of the participant to meet the costs of their own rent. Council will undertake further work on this issue in 2015.

9. <u>Undertake additional work to clarify the meaning of reasonable and necessary support in relation to Aboriginal and Torres Strait Islander (ATSI) people</u>

The complexity of issues related to reasonable and necessary for ATSI populations warrants its own work. The Council notes that the NDIA is currently delivering services in remote areas of South Australia and the Northern Territory, and is developing an indigenous strategy.

The Council recommends that the NDIA:

- brief the Council on innovative strategies that have been adopted in ATSI communities, and
- consult the Council on the development of the indigenous strategy.

10. <u>Undertake additional work to clarify the meaning of reasonable and necessary support in relation to people from culturally and linguistically diverse backgrounds</u>

The Council recommends further work be undertaken to understand reasonable and necessary support in relation to people from CALD backgrounds. The Council notes that the NDIA has already commenced this work.

11. <u>Make additional adjustments in relation to reasonable and necessary support for people in rural and remote areas</u>

Four Practical Design Fund projects explored the additional challenges faced by people with disability in rural and remote areas. As a result, the Council recommends that:

a) The greatest possible flexibility is applied in considering the reasonable and necessary supports of a participant in rural and remote areas. This includes supports that assist the participant and supports to enhance family capacity and resilience.
b) Further work is undertaken in relation to reasonable and necessary for travel
c) Where sustained benefit can be delivered via remote technology, reasonable and necessary support includes the purchase of appropriate technology.
d) Specific capacity building opportunities are designed for people in rural and remote areas. In addition, it is essential to enable equitable access to other opportunities by meeting the real costs of participation including family care, travel and accommodation.

Recommendations in relation to other NDIS responsibilities

12. Build the capacity of people with disability and families

Capacity building of people with disability and families is one of the key strategies under NDIS responsibility that can address some of the societal and service barriers that inhibit opportunities for an ordinary life. This is because capacity building provides the possibility of giving people a vision of an ordinary life that can act as a driver of change in demand in the service system and in society. In addition, demand for an ordinary life can reinforce the view that a life lived in services, surrounded by paid staff is not an ordinary life. This is a message critical for the sustainability of the NDIS.

The Council recommends

a) The urgent implementation of the Disability Support Organisation (DSO) initiative.
b) That the NDIA works with Disability People's Organisations and advocacy organisations to co-design a national infrastructure to ensure that capacity building is an ongoing responsibility of the NDIS rather than a short-term project based strategy.

13. Local Area Coordination

Local Area Co-ordination (LAC) is a key NDIS strategy to assist people with disability to be included in their communities. Council notes that in rural and remote areas, people with disability and families have sought a more active role in community development to support the emergence of local networks and self-help initiatives. Its continued development and refinement in the lead up to full Scheme transition will support maximum impact.

The Council recommends that the Agency consider whether alternative arrangements are required for rural and remote areas.

Other targets for change in building an ordinary life

14. Risk enablement

The current service approach to risk is increasingly placing barriers to an ordinary life of people with disability. Service providers are reluctant to share risk with consumers and reluctant to even discuss the issue of risk and safeguards in forums with consumers. As the major future funder of supports, the NDIS is well placed to facilitate discussion between providers and consumers on the issue of risk in an effort to reduce the negative impact current risk management is having on choice and control of consumers.

The Council recommends that the NDIA facilitate discussion between peak service providers, representatives of people with disability, and advocacy and capacity building organisations with a view to supporting moves to a framework of risk enablement.

The Council notes that it intends to provide its own advice on best practice approaches to ‘reasonable risk’ in early 2015.

Section 1 Introduction

‘Reasonable and necessary support’, a key concept in the NDIS, is the nature and quantum of assistance to enable a participant to pursue goals and aspirations. Objects 1 (a), (c) and (e) of the NDIS Act begin to frame the nature of ‘reasonable and necessary’. The reasonable and necessary support must: *(a) give effect to Australia’s obligations under the UNCRPD*, *(c) support the independence and social and economic participation of people with disability* and *(e) enable people with disability to exercise choice and control in pursuit of their goals and in the planning and delivery of their supports.*

The general principles in section 4 further our understanding, requiring that reasonable and necessary support be provided for people with disability *to pursue their goals and maximise their independence (11(a))…to live independently and to be included in the community as fully participating citizens (11(b)) and develop and support the capacity of people with disability to undertake activities that enable them to participate in the community and in employment (11(c)).*

The support must meet six specific criteria which are contained in section 34 of the NDIA Act.

This paper brings together a body of work of the Council to provide guidance to the NDIA, participants and the Australian community about how an ‘ordinary life’, consistent with the objectives and principles of the NDIS Act could be used to guide what is reasonable and necessary support.

The paper will:

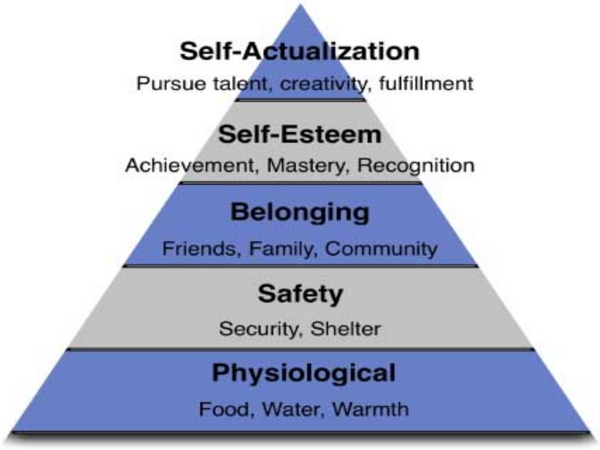
- Explore enablers of an ordinary life by summarising literature about promoting independence, genuine community engagement and a good life to identify signposts of an ordinary life to which the NDIS must assist participants to aspire.
- Explore barriers to an ordinary life at the societal, service and individual levels as well as identifying barriers that could be addressed by the NDIS.
- Identify special considerations to recognise and compensate for challenges faced by ATSI peoples, CALD and people living in rural and remote areas.
- Identify what an ordinary life might look across the lifespan and in specific domains of life.
- Explore the extent to which the NDIS cluster structure could be used to promote supports that build an ordinary life; and
- Conclude with general recommendations about reasonable and necessary support and other areas of provision over which the NDIS has responsibility.

Section 2 Enablers of an ordinary life

The psychologists Abraham Maslow[1] and Martin Seligman provide a framework for consideration of an ordinary life. Interestingly, both wrote about a ‘good life’ because outside the frame of vulnerable people who need government funded support, they had the confidence to aspire for more than ordinary. The lives of people with disability, however, start from a lower base – a life lived in services. This means that the first aspirations are for the ordinary – the aspects of life others take for granted. However, understanding factors that enable a good life will help guide what is needed for an ordinary life.

Maslow believed that individuals possess a set of intrinsic motivations that are hierarchical. A person has to meet his or her lower level (basic or deficit) needs prior to being able to ascend the hierarchy to achieve the highest order need, that Maslow described as self-actualization.

Maslow’s hierarchy of needs



The deficiency, or basic needs are said to motivate people when they are unmet and the longer they remain unmet, the stronger the motivation to fulfil them. Maslow argued that without satisfaction of one’s basic needs for physiological security, safety and belonging, one could not achieve self-esteem, an essential prerequisite to self-actualization.

Thus for Maslow, a good life comes from meeting one’s basic needs (that include the need for friends, family and community as well as for achievement, mastery and recognition) in order to fulfil one’s potential.

Psychologist Martin Seligman[2], leading writer in Positive Psychology, frames a discussion on a good life through the prism of happiness. Seligman describes happiness as having three dimensions that can be cultivated: the ‘Pleasant Life, the Good Life and the Meaningful Life’. The ‘Pleasant Life’, experienced as

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[1] Maslow, A, http://www.learning-theories.com/maslows-hierarchy-of-needs.html.
[2] Seligman, M., *Authentic Happiness: Using Positive Psychology to realise your potential for lasting fulfilment, NY Free Press*, 2002.

positive emotions, is realized if we learn to savour and appreciate such basic pleasures as companionship, the natural environment and our bodily needs. He argues that we can remain stuck at this stage or we can go on to experience the 'Good Life', which is achieved through discovering our unique virtues and strengths and employing them creatively to enhance our lives. Seligman describes this as the engaged life and research demonstrates this is enhanced by positive relationships, a sense of belonging and involvement in activity that offers a challenge.

According to modern theories of self-esteem[3], life is only genuinely satisfying if we discover value within ourselves. One of the best ways of discovering this value is by nourishing our unique strengths in contributing to the happiness of fellow human beings. Consequently, the final stage of happiness according to Seligman is the 'Meaningful Life' in which we find a deep sense of fulfilment by employing our unique strengths for a purpose greater than ourselves.

The importance of relationships

Relationships stand out as a significant contributor to health and wellbeing from multiple disciplines. Studies of older people may be particularly relevant, with the finding that social engagement and relationships are associated with health and wellbeing despite the presence of chronic health conditions, declining health and lower rates of being partnered.[4]

Research on promoting independence also reveals the critical importance of relationships in the formation of identity.[5] The stories people tell reveals how they shape their identity and that the stories are made possible by the networks to which they belong. Whilst young people with disability have the same hopes and aspirations as their peers without disability they have less opportunity to develop social networks and less opportunity to develop stories or narratives of themselves that draw on a wide range of resources and social interactions.[6]

Hence young people with disability have fewer opportunities to develop identity narratives that enable them to negotiate their way, as much of this social interaction is mediated by third persons (either a carer or family member). Their reduced social networks inhibit the development of identity and independence.

The importance of belonging

'Belonging' features in all understandings of a 'good life'. Maslow argued it was half way up the hierarchy of needs, a requisite once the most basic needs had been met. Belonging is critical for identity formation, providing the stories that shape who we are. The *South Australian Learner Wellbeing*

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[3] National Association for Self Esteem http://www.self-esteem-nase.org/research.php.
[4] Australian Government, Department of Health and Ageing, 2013, *Staying Connected.*
[5] Stokes, H, *Imagining Futures: Identity narratives and the role of work, education, community and family,* Melbourne University Press, Melbourne, 2012.
[6] Stokes, H, Turnball, M & Wyn, J, *Young people with a disability: independence and opportunity: a literature review* at http://web.education.unimelb.edu.au/yrc/linked_documents/research_report39.pdf.

Framework[7] includes positive relationships, feeling safe, connection and belonging as protective factors that influence wellbeing and student engagement within education and care setting. The absence of a sense of belonging, seen in poor connection to site, ineffective behaviour management and bullying are identified as risk factors.

Belonging and community engagement are associated with improved health and wellbeing, increased learning and increased productivity in research in relation to older people and in the fields of education and work.

The importance of economic participation

Health and wellbeing are consistently shown to be associated with employment with longitudinal studies demonstrating that employed people report significantly lower levels of health disorder than students and the unemployed.[8] Marmot's work for the World Health Organisation[9] on social determinants of health confirm these findings.

However, the health consequences of employment and unemployment are directly contingent upon quality of work. Unsatisfactory and insecure jobs do not provide the same benefits in relation to health and wellbeing. Marmot shows that the health effects start when people first feel their jobs are threatened even before they actually become unemployed. This shows that anxiety about insecurity is detrimental to health. Job insecurity has been shown to increase effects on mental health (particularly anxiety and depression), self-reported ill health, heart disease and risk factors for heart disease. Because very unsatisfactory or insecure jobs can be as harmful as unemployment, job quality is important.[10]

The importance of a challenge

Research in brain theory recognizes that deeper learning occurs when young people are provided with experiences and environments that encourage active involvement with their learning. This is confirmed by Koen and Duigan (2008)[11] who found that students are more likely to be involved in learning activities which are challenging, relevant and meaningful and which are tailored to their interest, strengths and aspirations. Stokes et al.[12] confirm this with research that demonstrated that optimal learning occurs

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[7] Dept. of Education and Children's Services, South Australia *South Australian Learner Wellbeing Framework*, 2007.

[8] Graetz, B, Health consequences of employment and unemployment: Longitudinal evidence for young men and women, Social Science & Medicine V36, N6, 1994, p. 715–724.

[9] Wilkinson, R, & Marmot, M, *Social determinants of health: the solid facts,* World Health Organisation at http://books.google.com.au/books?hl=en&lr=&id=QDFzqNZZHLMC&oi=fnd&pg=PA5&dq=impact+of+social+and+economic+participation+on+health+and+wellbeing&ots=xUoJeESKlp&sig=n7I97INA-6rzO8pMLFU89L3Yi8g#v=onepage&q&f=true

[10] Butterworth, P, Leach, LS,Olesen, S, Rodgers, B, Broom, D, *The psychosocial quality of work determines whether employment has benefits for mental health: results from a longitudinal national household panel survey*, 2011 at http://oem.bmj.com/content/early/2011/02/26/oem.2010.059030.abstract

[11] Koen S & initial Duigan *Forging Brighter Futures, paper presented a History and Future of Social Innovation Conference*, *Adelaide*, *19-21 June*, 2008.

[12] Stokes, H, Turnball, M & Wyn, J op. cit.

when people take on a task that offers a challenge but sits beyond their existing range of skills, creating a learning opportunity.

Seligman recognises the importance of a challenge in achieving an engaged or good life. He believes discovering our unique virtues and strengths and employing them creatively to enhance our lives provides a challenge that improves the quality of life. Challenge that contributes to a purpose greater than us and to the happiness of others is a feature of a meaningful life.

Independence

Independence is a concept that is highlighted in the NDIS legislation. In the context of disability, independence does not confine itself to such traditional criteria as living in one's own home or being employed. The UNCRPD emphasises that independence for persons with disabilities encompasses:

- individual autonomy
- the opportunity to be actively involved in decision making processes, and
- the opportunity to access the physical, social, economic and cultural environment.

Rock (1988)[13] argues "*Independence for young people with disability means having choice and control of their life and their environment*".

It is important to balance independence with the basic need to be valued and loved, recognising that relationships with people who care about (not necessarily care for) an individual provide the most significant safeguard for a vulnerable person. As a result, this paper argues that independence is best achieved in equal valued partnership with others, i.e. as interdependence.

Three themes emerge from the literature that focuses on factors that impact on opportunities for independence: identity development, resources and support and attitudes.[14]

Research about the importance of networks in shaping identity has been identified above. Opportunity for meaningful decision-making is another critical element in the development of identity but research has shown that young people with disability 'lack voice' in decisions about their lives.

A number of studies identify family support (attitudes and material resources) as the single most important contributor to a young person being able to maximize independence and transition into adulthood. The general attitudes of society, however, continue to be a barrier to independence whereby stereotypical assumptions and low expectations make people with disability feel invisible, not respected and excluded.

Research affirms that the goal of independence requires that people be supported to maximize their self-determination and self-direction, be supported to have meaningful choices, make meaningful

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[13] Rock, P (,*Independence: What it means to six disabled people living in the community. Disability and Society* 3(1), 1988, pp. 27-35.

[14] Stokes, H, Turnball, M & Wyn, J op. cit.

decisions about their life and have access to the same opportunities in their physical, social, economic and cultural environment as their peers without disability.

Common themes across the literature

The literature identifies a number of themes associated with positive health and wellbeing and features of the ordinary life to which we all aspire. Earlier the dilemma between aspiring to a good life and an ordinary life for people who need government funded support was noted. People with disability were described as feeling nervous about asking for a good life lest ‘good’ conflicts with sustainable. Interestingly, this literature demonstrates that the features of a good life come from things that ‘money can’t buy’, including:

- positive relationships
- a sense of belonging
- individual autonomy
- active involvement in decision making
- active engagement in the physical, social, economic and cultural community
- using our unique strengths in ways that provide a challenge, and
- making a contribution.

Enablers of an ordinary or a good life come from the approach used in the reasonable and necessary support, not the quantum of that support itself.

The enablers of an ordinary life in relation to the NDIS Act

The NDIS legislation provides the foundation to enable Australians with disability to aim high under the framework of the UNCRPD. The guiding principles confirm that people with disability have the same rights as other members of the Australian society to *‘determine their own best interests, including the right to exercise choice and control, and to engage as equal partners in decisions that will affect their lives, to the full extent of their capacities.’* The enablers provide evidence-based guidance as to the path most likely to reach positive outcomes reflective of their goals and aspirations.

The Council recommends that reasonable and necessary support should facilitate the enablers of an ordinary life, namely positive relationships, belonging, achieving autonomy, active involvement in decision-making, opportunities for challenge and contribution. This should be facilitated through conscious attention to the enablers in planning conversations, capacity building opportunities, and in service provision.

Section 3 Barriers to an ordinary life

Societal barriers

A lack of social inclusion and multiple barriers to meaningful participation in the community were the most frequently raised issues in the submissions and consultation of National People with Disabilities and Carer Council reported in the *Shut Out* Report (2009).[15] Of the submissions, 56 per cent identified exclusion and negative social attitudes as critical issues,[16] suggesting that there are still widespread misconceptions and stereotypes informing the attitudes and behaviour of service providers, businesses, community groups, government and individuals.

Negative attitudes and misconceptions are often built on a view of disability as tragedy and while almost everyone would avoid its challenges, such attitudes have a profound impact on the relationship others extend to a person with disability. Misconceptions create a view of people with disability as dependent clients who need to be cared for rather than citizens who want the same basic things as everyone else and may need some assistance in order to contribute. Misconceptions turn the unique role and authority of parents into a status of carers that confuses people who deeply love and care about a person with people who are paid to provide service (and often do not care a great deal).

The built environment continues to be a major barrier to an ordinary life for many. Of the *Shut Out* Report submissions, 27 per cent indicated that the lack of access to buildings and facilities is a barrier to full participation, while 29 per cent identified a lack of access to transport as a significant barrier. Whilst it is not the responsibility of the NDIS to overcome these barriers, their existence provides additional challenges for reasonable and necessary support for an ordinary life.

Barriers from the service system

More than half of the submissions to the *Shut Out* Report indicated that services and programs act as a barrier to, rather than a facilitator of, their participation.[17]

Learned dependence created through inappropriate and often excessive use of paid support can be a significant barrier to an ordinary life.

Whilst the service and education systems talk about promoting independence, there are many practices that promote dependence. Old style early intervention often left parents with the message (often unspoken) that children learn best in one to one interaction with a skilled adult. The value of environmental learning from peers, from interaction with family and from free play was underplayed. It led many parents to seek wrap around support (from teachers' aides) in early childhood settings and in school. Whilst this is less the case in contemporary practice, the fact that most early intervention continues in segregated settings contributes to parental demand for full time support that gets in the way of forming relationships with peers and moves to independence.

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[15] National People with Disabilities and Carer Council,*Shut Out*, 2009, p. ?.
[16] National People with Disabilities and Carer Council, Op cit. p. 3.
[17] Ibid., p. 4.

The vast majority of schools, both regular and special have a tendency to velcro staff to students creating learned helplessness and dependence and thwarting the development of natural networks of helpful friends. Whilst some students do need significant support, that support must be crafted very carefully in order to facilitate opportunities for other children to interact and assist where necessary. Enabling children with disability to learn to appropriately ask their friend or classmate for assistance is a skill of independence that cannot be acquired if adults surround a child.

Disability services also provide support in ways that promote dependence. The much sought after individualised funding is too often used as a paid friend with whom a child, young person or adult can share an outing. Whilst pleasant at the time, paid friendship promotes dependence and only creates the demand for another slot of paid friendship. Where support workers are guided by expert facilitation and trained to understand their role as life facilitators rather than paid friends, their efforts are much more likely to lead to opportunities for relationships with community members and a sense of belonging. This is a necessary underpinning to enable individualised support to foster an ordinary life.

Service models that group people with disability significantly impede opportunities for an ordinary life. Group homes and day programs have developed under the guise that people with disability are better off with 'their own' and because limited imagination anticipated that all support had to come from paid workers. Research affirms better quality of life without necessarily additional cost when paid support is used to complement informal support of family and friends to enable people, including those with high support needs, to live in their own homes and enjoy valued roles in the community. However, what is often not recognised in funding formulae is that many people with disability do not easily form relationships with people who want to play a role in their lives and therefore investment in the development of informal support is required in order to enable this type of lifestyle.

The attitude of services to risk has a major impact on opportunities for an ordinary life. Fear of work health and safety claims have led services to avoid risk rather than mitigate risk through prudent planning and safeguarding. Ordinary activities become constrained as common sense gives way to restrictive processes robbing people of ordinary opportunities for a rich life.

Barriers in the individual and the family

The attitudes of many people with disability and their families are shaped by negative experiences of being segregated, excluded, marginalized or ignored. This reinforces low expectations and often leads to the self-fulfilling prophesy of lives deprived of meaning and contribution.

Where people are not exposed to different ways of doing and to different ways of living, they are deprived of opportunities to see that despite significant disability, people can lead independent valued lives included in their communities. Capacity building is the key.

Opportunities for the NDIS

Quality plan implementation support

Participants who have moved from the NSW self-managed *Community Participation*[18] Program to the NDIS in the Hunter Trial Site have been disappointed. It appears to participants and their services that in general, the NDIA only pays for direct support and makes no active provision for the information and skilled facilitation they valued under shared management. Families perceive that in general the skilled facilitation was responsive to their needs and abilities and enabled them to:

- facilitate life planning from aspirational goals to the micro steps required to achieve an outcome
- take responsibility for staff recruitment, support and supervision
- pay for the professional development of staff, and
- undertake support coordination.

Most people with disability and families in the Hunter trial site have not been aware that these are 'services' they need to request and anecdotal evidence indicates that participants looking for infrastructure to underpin direct support have been allocated as little as ten hours of support coordination per annum.

In an insurance framework, quality plan implementation support represents an important upfront investment that will lead to improved and more sustainable outcomes for participants.

The Council recommends that the quality plan implementation aid required to provide life building support for an ordinary life is considered an essential element of reasonable and necessary supports.

<u>Ensure opportunities for participants to select their own staff</u>

One significant change for these participants is that when staff that have been personally selected leave, the participants are prevented from advertising[19] and are forced to use staff of the service provider rather than individual selection. Participants describe this impact as devastating when allocated staff do not share their interests and lack the skills to facilitate relationships rather than be a paid friend.

The Council recommends that the NDIA considers how participants could be supported to select their own staff, instead of relying on service providers to do this on their behalf.

<u>Enable participants to purchase training in specific skill sets for staff</u>

Participants value the opportunity to provide the training for support staff that prepares them for the roles desired. Training in SRV (Social Role Valorisation) and Active Support, for example, are not yet core competencies of support workers and even if they were, many participants prefer to employ people who have never worked in the disability sector, believing it is easier to teach skills to people with solid

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[18] Self-managed *Community Participation* is a NSW program for school leavers that uses a shared management approach, giving complete control over factors of support to people with disability and families. Many participants take responsibility for functions such as staffing and support coordination. Others value the control self-managed *Community Participation* gives them over lifestyle decisions but retain the value added Infrastructure that underpins life-building support from the service.

[19] Service providers argue that unit costs under the NDIS prevent participants from advertising for their own staff.

values and shared interests than to work with staff who do not share interests. The lack of provision for staff training is a serious barrier for some participants.

The Council recommends that in developing the workforce strategy, and in undertaking further work on the efficient price, that consideration be given to how targeted training can be provided to staff that require a specific understanding or skill in order to meet the support needs of a participant.

Planning within NDIA

Planning assists participants and their families to move from clients of a capped, crisis oriented state system to citizens purchasing reasonable and necessary supports to meet their disability support needs.

The planning process must help a person think about goals, and aspirations, and operationalise them through strategies ultimately recorded as a statement of supports. Many participants will never have considered having goals and aspirations, and considering this in the company of a stranger (consisting of an NDIA representative) would not necessarily help to stimulate conversation.

Many participants will never have been asked to think about goals and aspirations before and this will be made more challenging as their guide in this exploration will be a stranger from the NDIA.

A constraint on the NDIS planning process is the pressure of time. Signoff of the plan is not just about activating support for the individual. It is also about enabling the transition of funding from states and territories into the NDIS. As so many people need to make that transition, one of the outcomes reported by the Scheme is the pace of transition – the number of days to determine participant eligibility and the number of days for the approval of the plan. Whilst these indicators reflect understandable pressures for the Scheme, they conflict with a primary concern for the best interest of the individual.

The Council has expressed the view that the planning process as currently framed is not likely to achieve the best opportunity for an ordinary life; that provision for life planning outside the Agency is more likely to facilitate the development of informal support, which is critical in reducing participant reliance on paid support.

The Council recommends that every participant should be provided with access to support for life planning, the results of which will be submitted to the NDIA for consideration as a plan—noting that in accord with the NDIS Act, the NDIA would need to ensure that the supports aligned with the participants' goals and aspirations.

Consider the infrastructure necessary to provide life-building support

Section 7 in the paper argues that the current organisation of support clusters does not promote planning that facilitates the enablers of an ordinary life. The information from pricing clusters provides little or no guidance to help planners assist participants to think about how they can achieve positive relationships and a sense of belonging; individual autonomy; active involvement in decision making; active engagement in the physical, social, economic and cultural community; and how participants can use their unique strengths in ways that provide a challenge and enable them to make a contribution.

The reorganisation of this information is important to maximise aspirations and facilitate opportunities for an ordinary life.

Consider innovative ways that supports can be provided, including through home share arrangements

Whilst the Agency has increased flexibility of provision by bundling a number of supports, there are other innovative practices that facilitate opportunities for an ordinary life and also provide value for money.

The Council recommends that the NDIA considers innovative ways of enabling support to be provided. For example, the Council recognises existing practice whereby people with disability encourage individuals without disability to live with them and provide informal supports in return for subsidised rent.

While the Council supports this approach, it notes that it is always the responsibility of the participant to meet the costs of their own rent. Council will undertake further work on this issue in 2015.

Building the capacity of people with disability and their families

This paper has canvassed barriers to an ordinary life at the societal, service and individual level. Most are outside the responsibility and control of the NDIS. Capacity building of people with disability and families is, however, the single most powerful step under the control of the NDIS that can assist in removing the barriers.

Parents who have a vision of an ordinary life for their sons and daughters will have a vision that assists them to argue against models of service provision that take them away from the path to an ordinary life. They will argue against, rather than for, full time teachers aides, understanding that teacher aides often create dependence and impede opportunities for friendship and help from classmates. They will argue for core competencies in support workers to help facilitate relationships for their family member with disability rather than being content with a paid friend.

Much has been written about the importance of capacity building.[20] The fact that current capacity building is funded through non-recurrent initiatives of state and territory governments has a serious impact on opportunities for an ordinary life and is seen in the continued demand for 'more of the same' in NDIS packages. Without capacity building, the NDIS will enable participants to be consumers, rather than dependent clients, of services who have some choice but limited opportunity to avail themselves of the choice and control anticipated in the NDIS. It is only capacity building that will support people to be active citizens exercising choice and control and in engaging in social, economic and political life.

The Council recommends

a) The urgent implementation of the Disability Support Organisation (DSO) initiative.

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[20] KPMG, *Interim Report: Review of the Optimal Approach to transition to the full NDIS*, 2014, Parliamentary Joint Standing Committee on the National Disability Insurance Scheme, *Progress Report on the implementation and administration of the NDIS*, July 2014.

b) That the NDIA works with Disability People's Organisations and advocacy organisations to co-design a national infrastructure to ensure that capacity building is an ongoing responsibility of the NDIS rather than a short-term project based strategy.

Other targets for change in building an ordinary life

1. Risk enablement

The current service approach to risk is increasingly placing barriers to an ordinary life for people with disability. Service providers are reluctant to share risk with consumers and to discuss the issue of risk and safeguards in forums with consumers. As the major future funder of supports, the NDIS is well placed to facilitate discussion between providers and consumers on the issue of risk in an effort to reduce the negative impact current risk management is having on choice and control of consumers.

The Council recommends that the NDIA facilitate discussion between peak service providers, representatives of people with disability, and advocacy and capacity building organisations with a view to supporting moves to a framework of risk enablement.

The Council notes that it intends to provide its own advice on best practice approaches to 'reasonable risk' in early 2015.

Section 4 Special Considerations for Aboriginal and Torres Strait Islander people

There is a growing body of literature about providing culturally appropriate services and supports to Aboriginal and Torres Strait Islander (ATSI) people and their communities. In the NDIS space alone there were six Practical Design Fund Projects (2013) that focused on ATSI issues including understanding indigenous concepts of disability, improving cross cultural understandings, developing carers groups and leisure activities, providing guidance to enable mainstream organisations to work effectively with ATSI people with psychiatric disability and brain injury and work to increase the number of indigenous people in remote communities who are trained as disability support workers.

Rather than including a brief commentary here, a specific piece of work is required to provide commentary on the additional considerations needed to ensure that reasonable and necessary support is framed and provided in ways that enable ATSI people with disability to thrive.

To summarise reflections from the Arafmi project that focused on indigenous families and carers of people with psychiatric disability in remote West Australian indigenous communities:

> *The NDIS framework needs to be highly flexible, based on person centred planning and adaptable to the wisdom of local kinship, social and cultural imperatives including traditional practices. Indigenous people need to be included and trained in real decision*

> *making when it comes to applying and managing the NDIS for individuals with psychiatric disability within their communities. The issue is not always about the individual but the contextual framework of the indigenous community and their traditional values and belief systems.*
>
> *The NDIS needs to tap into the complexities of indigenous culture, existing sector knowledge and expertise and to identify practical solutions and innovative approaches…We have to re-think our entire approach to these challenges and we should be open to this. The risk is, if we don't, the scheme may fail indigenous Australians with disability, their carers and families, and perhaps other people with disability…Indigenous 'ownership' of the NDIS is imperative if the aims and objectives of this scheme are to be achieved.*

The reflections concluded with a quote from Champion, A. 1996 *Emotional and Social Wellbeing*, Perth WA:

> *It is about reclaiming our tribal autonomy, authority and identity as both local tribal people and indigenous people…the environment, our land, our place of belonging-ness, our stewardship roles and responsibilities, our healing processes….To do this, the local traditional customs, protocols and practices must be observed and adhered to…all these things constitute our physical/spiritual/emotional/mental wellness and well-being.*

Recommendation

The complexity of issues related to reasonable and necessary for ATSI populations warrants its own work. The Council notes that the NDIA is currently delivering services in remote areas of South Australia and the Northern Territory, and is developing an indigenous strategy.

The Council recommends that the NDIA:

- brief the Council on innovative strategies that have been adopted in ATSI communities, and
- consult the Council on the development of the indigenous strategy.

Section 5 Special considerations for people of culturally and linguistically diverse (CALD) background

Cultural responsiveness consists of the framework for planning and delivering services that are respectful of, and relevant to, beliefs, practices, culture and linguistic needs of individuals and communities. Literature on the topic of cultural responsiveness and cultural safety in service provision for people with disability recognises that disability issues have a significant set of cultural overlays that impact on all aspects of disability awareness and service relevance and response.

Key themes include:

- Disability is a sensitive issue in many communities with varying degrees of stigma that negatively impacts on, for example, receptiveness to messages about disability, lifestyle expectations and service access.

- Disability has different meanings in different cultures and this can impact on the way in which the person is treated and supported.
- Service expectations and access may be influenced by previous experiences with disability in different cultural contexts. This learned behaviour might have an impact (either positive or negative) on how disability services are understood, seen as relevant or used.
- Culture and language specific pathways may either allow greater access because of linguistic and cultural relevance or may impede access due to prevailing stigma around having a person with disability in the family or community. This means that for some, ethno-specific services may be a preferred, but for others, assistance outside the community is desirable.
- Providing support for a person with disability in many CALD communities is seen as the responsibility of family members and this may impact on perceived need for external support or services.
- The capacity of the individual or family to access services may be restricted due to limited awareness of available services, limited skills to receive services and low levels of confidence in expressing preferences or questioning service quality.
- These factors compound, causing people of CALD background to seek support at the point of crisis when needs have become complex and can no longer be sustained through informal care.

The cultural responsiveness of services may be a significant barrier to people getting the assistance they need. It is the responsibility of the NDIS to develop and implement a cultural responsiveness framework that addresses issues of:

- systemic capacity through the development of policy objectives, procedural requirements, resource supports and monitoring mechanisms to support culturally responsive service provision, and
- individual NDIS staff member competency to ensure that all NDIS staff have the knowledge and skill sets necessary to understand and interact with CALD people with disability in family and community settings and have the attitude to develop relationships based on mutual respect.

Once again, it would be difficult to provide a small commentary on the additional considerations required to ensure that reasonable and necessary support is provided in ways that enable CALD people with disability to thrive. A specific piece of work is required.

Recommendation

The Council recommends that the NDIA undertake further work to understand reasonable and necessary support for people of culturally and linguistically diverse backgrounds. The Council notes that the NDIA has already commenced this work.

Section 6 Special considerations for people in rural and remote Australia:

> *...When you get respite or you get support from a disability service, it is for that one child. So if you have got two kids at school, the kid with disability can be picked up and the other one can't, so that doesn't support a family at all.*
>
> *We had a dietician make an appointment to see me about a month in advance. We rearranged our whole lives for this appointment. Then they rang and said 'Oh, we don't feel like coming to Tin Can Bay'. They didn't reschedule the appointment and we ended up having an over the phone talk. They said, 'There's nothing we can do for you'. It was a total waste of our time.*
>
> *Transport and travel costs are a huge burden for rural families e.g. petrol to get to appointments. The Patient Travel Subsidy Scheme is too burdensome, too hard to access and too many forms to fill in and only covers some travel costs.*
>
> *I have had the Better Start funding. It costs me $125 gap fee for a psychologist session – and that is for a phone consultation only. I couldn't afford it. And my kid was trying to grab the phone and hang it up so I would give them my attention and play with them, not talk on the phone [Cooloola Cove].*
>
> *In the first year, our baby required specialist visits and early intervention. Each specialist visit entailed me packing two small babies on to a plane, and spending a week 3500 km away from home. Thankfully PATS covered the cost of this, but it was still a gruelling and disruptive trip. I was lucky in that I had family who could accommodate and assist me in Perth, but I know of many others – who have had the same experience, and found themselves alone, vulnerable and without financial and social resources. For single parents this situation was far worse as the PATS didn't cover the cost of another child, and in some cases there was no one to look after an older sibling.*

These are the voices of families of people with disability who contributed to a roundtable organised by the National People with Disability and Carer Alliance and the National Rural Health Alliance to discuss equitable service delivery to people living with a disability in rural and remote areas.

A number of Practical Design Fund projects focused on issues related to geographical isolation reporting on:

- The profound interconnection of people with disability and their family member with disability:

  > *It's not only about the person with disability in rural and remote areas; it's also about their families, the effects it has on siblings, for example, and on relationships and single parent families.*

- The frustration with 'fly in fly out' and 'drive in drive out' services, drawing on experience in Meekatharra and nurses with the Flying Doctor Service to argue that 'the longer the stay, the better the outcomes’.

- The amplification of the burdensome effects of disability with the challenges of remoteness.
- The contrast in quality and availability of disability support services between major cities and remote areas.
- The lack of capacity in over-stretched towns to deal with disability.
- The transience of non-indigenous people in very remote areas that makes it very difficult to form support networks that would help with the raising of a child with disability.
- The transience of service staff that impacts on the quality of care and relationships within therapy teams.
- The isolation that comes from a lack of services including GP and counselling.
- The lack of, and prescriptive nature of, respite services.
- The lack of suitable alternative activities for people with disability.

These challenges translate into key messages for ‘reasonable and necessary supports’ and the general operation of the NDIS including:

1. <u>Flexibility</u>

The strongest message related to the critical importance of flexibility and pragmatism in the application of rules; that common sense must trump rules and bureaucracy every time.

The additional level of flexibility is required in rural and remote areas because the lack of formal services can result in the unrelenting pressures on families in caring for a person with disability. People report that a simple lack of flexibility has made life so much more difficult for people than what it need be. Families argued strongly that they know what will make a difference and their views should be respected and supported, utilizing local capacity in innovative and in impromptu ways.

Reports of seminars that enable people to discuss the challenges of living in geographically isolated areas provide a wealth of examples of ways to support a family, some of which are covered by NDIS and state service policy and practice and some of which are not. Examples include:

Minding the siblings:

> *A family may need to take their child with disability to a major city for a medical consultation, minding the child’s siblings becomes an issue that can be solved by a flexible package that enables a local person to be paid to perform this role.*

Somebody to cook a meal:

> *...We have had access to allied health services and we have had access to health but that is not actually what we need. When my daughter wakes at 2 a.m. and screams for five hours and then spends many hours screaming during the day, I have no capacity to do my housework, no capacity to do what my son needs; so sometimes what I need is housework. Maybe somebody will cook a meal for me. Respite, God help us, yes, absolutely, we need that…Sometimes we need really simple stuff. Child-care, for example, we were accessing, three different child-care services for my daughter because the child-care services weren't able to cope with her area of disability.*

Money to spend as they chose to support their family:

> *In Queensland we had what was called the flexible family support until the government took the "flexible" out of it and it became "family support". It provided just a basic amount of money for families to spend as they chose to support their family; not just the child with a disability, but siblings as well, so you could spend on house cleaning, whatever it took to keep the families together. And Queensland has defunded that now.*

Recommendation

The Council recommends that the greatest possible flexibility be applied in considering the reasonable and necessary supports of a participant in rural and remote areas. This includes supports that assist the participant and enhance family capacity and resilience.

2. <u>Transport</u>

Distance to access services, travel costs and lack of transport options were all identified as significant issues by many participants.

> *Transport and travel costs are a huge burden for rural families e.g. petrol to get to appointments. The Patient Travel Subsidy Scheme is too burdensome, too hard to access and too many forms to fill in and only covers some travel costs.*
>
> *We need a good transport system, not taxis, that you could ring and book to take you where you need to go when you need it. Taxis are too expensive out here. And that taxi voucher application form is rubbish. Too complicated, 11 pages of paperwork are too much! GPs are spending all their time filling in forms. Simplify the system and make it easier to access.*
>
> *I need help affording the travel to services. Keeping a car on the road is very difficult.*

The NDIA makes provision for travel in rural and remote areas. It is too early to determine its impact at current levels.

Recommendation

The Council recommends that the NDIA review provision for travel in the light of experience and advocate for a reduction in red tape associated with the Patient Travel Subsidy Scheme (PTSS).

3. Technology

Using Practical Design Fund assistance, Autism Queensland explored the use of technology in a small study designed to extend early intervention services for children with Autism Spectrum Disorder (ASD) in rural and remote locations in Queensland.

The study found that remote technology worked well for some families resulting in reduction in costs, increased flexibility in program format, provision of regular support, reduction in stress, increased convenience of being assisted in one's own home, reduced time and travel, up-skilling and education and the opportunity for team connection through the capacity to simultaneously 'bring everyone together', ensuring that everyone on the child's team was 'on the same wavelength'.

Remote technology did not however work for all families. Face to face program delivery was considered an essential pre-requisite and remote technology was not considered suitable for families in crisis or those who required more intensive support. Its drawbacks for people and therapists who did not have particular technology or confidence in their technology was noted as was the need for substantial information technology (IT) support to trouble shoot IT related problems.

However, overall, technology was seen as a viable option to increase access to service provision for some people.

Recommendation

Where sustained benefit can be delivered via remote technology, reasonable and necessary support includes the purchase of appropriate technology.

4. Empowering individuals

There was concern to ensure that isolation did not prevent people with disability and families from gaining a new vision of what is possible in contemporary Australia. The availability of subsidies and funding to cover the costs of conferences, informal networking, linking groups and sharing resources were thought to be important. It was noted that meeting the real costs of participation in capacity building forums might include transport to and from the venue, accommodation and participation support.

Recommendation

The aforementioned specific capacity building opportunities are designed for people in rural and remote areas. In addition, it is essential to enable equitable access to other opportunities by meeting the real costs of participation including family care, travel and accommodation.

5. Role of Local Area Coordination and capacity building in communities

Many participants have experience of state Local Area Coordination (LAC) and believed it was a vital ingredient in building better lives for people in rural and remote areas. People acknowledged that the effectiveness of the LAC model was relationship based and hence key elements of enabling success included basing LACs in smaller rural communities not just regional centres, ensuring areas are of a manageable size and enabling a caseload that supported effective assistance.

The preference for services and supports that are local, flexible and small was a clear message from the PDF project in north Queensland. A Local Area Co-ordinator could play a pivotal role in supporting the emergence of local, flexible, small collectives/networks and self-help initiatives.

Recommendation

The Council recommends that the role of the LAC continue to be trialled and refined in the lead up to the Full Scheme transition.

The Council recommends that the Agency consider whether alternative arrangements are required for rural and remote areas.

Section 7 An ordinary life across the lifespan

The lifespan approach recognises that people have the potential to grow and develop at any stage of life and that the growth and development is influenced by biological, cognitive, socio-emotional and contextual factors. It is a most appropriate framework for considering support for people with disability and is used in this report.

The lifespan approach[21] guides the NDIS to enable each participant to positively experience the key features of a life stage that their peers without disability take for granted. It provides a framework to respond to the contextual and historical circumstances that shape a participant’s life story as well as to the life changing events that have had a significant influence on making the person who they are today.

Appendix A examines reasonable and necessary support for people with disability in cohorts of birth to 2, 2–5, 6–12, 12–15, 16–25, 26–55 and over 55. The ordinary life analogue highlights the milestones and goals of peers who do not have a disability since both the UNCRPD and research confirm that people with disability want and have a right to the same opportunities as their peers without disability. The difference lies in the support required to achieve those aspirations. The tables of Appendix A outline goals, outcomes and supports to enable people with disability to lead ordinary lives typical of their peers in 21st century multicultural Australia.

This work has gone some distance to unpack support required. It will not have an impact on the lives of people with disability without additional work to strengthen each planning conversation to take these features into account.

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[21] Baltes, 2003 at https://www.inkling.com/read/human-development-diane-papalia-ruth-feldman-12th/chapter-1/paul-b--baltess-life-span

Recommendation

That the NDIA undertake additional work necessary to operationalise this material for planners.

Section 8 Information about reasonable and necessary support in the organisation of support clusters

In developing this report a designated senior planner in Barwon was consulted in order to go through a number of client profiles and scenarios with a view to understanding the way in which the NDIA would respond to the requests for reasonable and necessary support. The planner used the document *Support Clusters Definitions and Pricing for Victoria* to clarify the nature of services and supports that may be provided.

The support cluster document is designed to estimate and approve the costs of individualised plans, providing information on maximum or benchmark prices of identified supports. Service providers have been required to register to provide services for specific clusters as described in the document.

The document indicates, ‘Planners should refer to the *Guide to Understanding Funded Supports’*.

It is important to stress that the document is designed for use by the NDIA, not by consumers but it does provide insights into the way in which the Agency understands and responds to requests.

The question of interest is the extent to which the organisation of support clusters could be utilised to promote planning that facilitates the enablers of an ordinary life. That is, do the descriptors and limited commentary of clusters and line items guide planners to help participants think about how they can achieve positive relationships and a sense of belonging; individual autonomy; active involvement in decision making; active engagement in the physical, social, economic and cultural community; and how participants can use their unique strengths in ways that provide a challenge and enable them to make a contribution.

The observations in Appendix B demonstrate that by and large, with an experienced senior planner, the services and supports enabled through the clusters have the capacity to assist participants to have an ordinary life. The clusters more or less enable the support necessary to build a vision, develop informal support, strengthen the skills of a participant, enable a participant to become a volunteer, overcome barriers, enable resource supported decision-making, promote health and wellbeing, facilitate community inclusion, respond to behaviours of concern and unplanned events and support a participant to take on responsibility for aspects of service provision.

The key challenge however is to organize the clusters and describe their elements in ways that promote people thinking about the enablers of an ordinary life. Much of the quality infrastructure required for an ordinary life comes from the cluster *Assistance in co-ordinating or managing life stages, transitions and supports* where support item names and their simple descriptors such as *Co-ordination of supports,* *Life/transition planning* and *Mentoring and Peer support* do not do justice to the breadth of opportunities they enable.

The Council believes that the information provided about services and supports (the current Support Cluster document) should be reorganised for the purpose of providing greater clarity about NDIS enabled supports to build an ordinary life. The Council suggests it may prove useful to frame cluster descriptors in terms of elements of life that a person would want e.g. increased informal support. This might encourage more people to ask for this assistance and reduce planner variability in allocating these supports.

Recommendation

The Council recommends that:

a) There is an audit of guidelines on supports with consideration given to how these could be framed to enable participants to have an ordinary life.
b) The information provided about services and supports (the current Support Cluster document) is reorganised for the purpose of highlighting life tasks and supports to build an ordinary life.
c) The process of reframing information about supports is co-designed with people with disability, families, advocacy and capacity building organisations, service providers and the NDIA.
d) Steps are taken to gain greater consistency in supports provided in a plan, especially access to support coordination to implement a plan.

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Appendix A1: Key features of lifespan for Babies and Infants - Birth to 2

Issue	Babies and infants birth to 2
Key features of life stage	Babies form attachments to consistent adults Babies grow and develop through relationships and engagement with their parents and other caregivers in their family or community Well supported families create home environments that provide rich learning opportunities for children Informed families make better choices for their whole family Babies and infants participate in growth promoting experiences both at home and in community such as playgroups and childcare and informal family and community activities
What are young children with disability doing?	In families that are more stressed Developing at different rates Attending lots of appointments Attending early intervention Less likely to be at playgroup, childcare
Expectation that specialist supports will	Be goal oriented and responsive: directed to the needs and goals of individual as they change Be responsive and tailored to the needs of the individual Guide development by supporting new learning to be incorporated into everyday tasks, routines and activities providing real life experiences Support mainstream services so that learning is reinforced across all environments
Strategies to promote relationships and belonging	Capacity building for families to assist them to develop positive vision and a pathway Address family issues that might hinder development of relationships Use of informal care of grandparents, friends and babysitter Contact with other families of children with similar needs Participation in playgroups, childcare and other local informal networks Inclusion of child in age appropriate family, cultural and religious practices Contact with other families of children with similar needs
Strategies to enhance autonomy and decision making	Early intervention Build on strategies to promote relationships and belonging through: - assistance to make choices (doll or block), and - support to take action to get choice
Challenge	Play with other children through informal care, playgroups and day care Explore environment Being asked to do tasks within skill range

Appendix A2: Key features of lifespan for children 2 to 5

Issue	Children 2-5
Key features of life stage	Children grow and develop through relationships and engagement with their parents and other caregivers in their family or community Children acquire language skills and impulse control Well supported families create home environments that provide rich learning opportunities for children Informed families make better choices for their whole family Children participate in growth promoting experiences both at home and in community based settings such as playgroups and childcare and informal family and community activities
What are children with disability doing?	In families that are more stressed Developing at different rates Attending lots of appointments Attending early intervention Less likely to be at playgroup, childcare
Gap	Increased stress Less connected to community Early intervention Need for information, vision and pathway
Expectation of specialist supports	To be goal oriented and responsive: directed to the needs and goals of individual as they change To be responsive and tailored to the needs of the individual To guide development by supporting new learning to be incorporated into everyday tasks, routines and activities providing real life learning experiences To support mainstream services so that learning is reinforced across all environments
Strategies to enhance relationships and belonging	Capacity building for families to assist them to develop positive vision and a pathway Address family issues that might hinder development of relationships Use of informal care of grandparents, friends and babysitter Contact with other families of children with similar needs Participation in playgroups, childcare and other local informal networks Inclusion in local preschool or day care Inclusion of child in age appropriate family, cultural and religious practices Contact with other families of children with similar needs
Strategies to enhance autonomy and decision making	Early intervention Build on strategies to promote relationships and belonging through:

Issue	Children 2-5
	- assistance to make choices (doll or block) - support to take action to get choice , and - support to understand consequences of actions
Strategies to enhance challenge and contribution	Play with other children through informal care, playgroups and day care Explore environment Being asked to do tasks within skill range Attend childcare, preschool and school readiness activities High expectations including that child will help others

Appendix A3: Reasonable and Necessary support for children birth to 5 and their families

Issue	Goals	Outcome	Supports	System
Reasonable and necessary support for children birth to 5	To reach developmental milestones	Children will gain functional, developmental and coping skills that are appropriate to their ability and circumstances Children show evidence of self-determination in their everyday lives	Support to build a positive vision and a pathway	Tier 3
			Early intervention	Tier 3
			Support to coordinate health care needs	Health
			Toy libraries	Community
	To form attachments to consistent adults To enjoy relationships with siblings To live in well supported families that can create home environments that provide rich learning opportunities	Children participate meaningfully in family life Babies and infants are integrated into everyday life of their families	Support to facilitate functioning family Support for parents to care	Tier 3
			Encouragement to use of informal care of grandparents, friends and babysitter	Planning Tier 2 (ILC)
	To engage with parents and other adults in their family and community To participate in age appropriate family, community and cultural events	Children participate meaningfully in community life	Encourage inclusion in playgroups Inclusion support in early childhood settings Encourage family to include child in age appropriate family, community, cultural and religious practices Culturally competent services	LAC State and federal early childhood services
Vulnerabilities	To build congruence in everyday family life between needs of the child with disability and needs of other family members To strengthen integration of child with disability into their everyday family life	Well supported family that can care for all their children Avoidance of out-of-home placement and/or family breakdown	'Whatever it takes' supports to facilitate a healthy well-functioning family Behaviour support for child Encourage and assist to establish use of informal care of grandparents, friends, babysitters	Tier 3

Issue	Goals	Outcome	Supports	System
	and the community more generally To minimise concern about the effect of the child with disability on siblings both now and in the future		Support for inclusion in childcare	Cwlth & state govts LAC
Reasonable and necessary support for families	To support children to be ready for school	Children are ready to enter school and thrive	Capacity building	Tier 2 (ILC)
	To understand their child's development To understands how their child is progressing To have positive views of their child's developmental progress and future To support the child to participates in the traditions of the culture	Families understand their children's strengths, abilities and special needs.	Information Support to build a positive vision and pathway Parent advocacy understandings and skills Contact with families with children with similar needs	Tier 2 (ILC)
			Early intervention	Tier 3
			Encouragement to attend playgroups	All systems
			Childcare	Cwlth &state govts, community
	To advocate for services and supports for their child To be able to identify their needs and know how to access available services and supports To understand their rights and the rights of their child	Families know their rights and advocate effectively for their children	Parent advocacy and capacity building Practical support to participate in capacity building	Tier 2 (ILC)
	To understand the interventions needed to support the child	Families help their children develop and learn	Early intervention Capacity building	Tier 2 (ILC) and tier 3 early

Issue	Goals	Outcome	Supports	System
	To know what they can do to support their child's development To feel capable in parenting their child		Practical support to participate in capacity building	intervention
	To feel confident to access services and community activities To see themselves as partners with professionals To feel in control in selecting services and supports that meet the needs of their child and family To see themselves as equal and integral members of the team To work in partnership with service providers to meet the needs of their child.	Families are able to gain access to desired services, programs, and activities in their community.	Capacity building Early intervention Practical support to participate in capacity building	No systems listed here?
	To have people to call on for practical assistance as often as they need To have people to call on for child care as often as they need To have people to call on for emotional support as often as they need	Families feel supported	Address family issues that might hinder development of relationships Encourage and assist to establish use of informal care of grandparents, friends, babysitters Practical support Support to build congruence in everyday family life between needs of child with disability and needs of other family members	Tier 3
Systemic approaches	Communities have a range of service options and facilities to respond to	Early intervention services promote inclusion		Tier 1 information

Issue	Goals	Outcome	Supports	System
	emerging needs of families in supportive ways Communities value and welcome all members	Communities are welcoming		LAC/local govt and Tier 2 (ILC)
		Flexible work environments are responsive to the needs of parents of children with disability		Employment & Workplace Relations sector
		Health and education professionals have high expectations and support inclusive path for all children		Health Education Tertiary training

Appendix A4: Key features of lifespan for children 6 to 12

Issue	Children 6 to 12 or completion of primary school
Key features of life stage	Grow in independence Attend local school Increasing connection to peer group Changed relationship with family
What are children aged 6-15 without disability doing?	Attend local school Have friends Play sport Attend after school and vacation activities Participate in local social and recreational activities Get together with peers on the weekend
What are children with disability aged 6-12 doing?	In families that are more stressed Developing at different rates More involved with family members Less likely to have friends Less likely to be involved in out of school hours programs Use specialised transport to school
Gap	Increased stress Less connected to neighbourhood peers and community Less clear vision and pathway
Expectation of specialist supports	To be goal oriented and responsive: directed to the needs and goals of individual as they change To be responsive and tailored to the needs of the individual To guide development by supporting new learning to be incorporated into everyday tasks, routines and activities providing real life learning experiences To support mainstream services so that learning is reinforced across all environments
Strategies to enhance relationships and belonging	Strengthen relationships and belonging in family: • assist family to develop positive vision and a pathway • address family issues that might hinder development of relationships • encourage play with siblings and extended family, and • support the use of informal care of grandparents, friends and babysitter Strengthen relationships with peers and in community: • identify strengths and interests as basis for relationships • strengthen social and relationship skills • encourage play with neighbours • children attend local school, after school and vacation programs with peers • support to participate in age appropriate family, cultural and religious practices, and • support inclusion in local sports and interest groups

Issue	Children 6 to 12 or completion of primary school
Strategies to enhance autonomy and decision making	Support to make choices Support to take action to bring choice to fruition Support to understand consequences of actions
Strategies to promote challenge and contribution	High expectations at school and in all activities Expect child to help others Expect services/ activities to require child to do tasks appropriate to his/her skills

Appendix A5: Key features for children 13-15

Issue	Children 13 to 15
Key features of life stage	Grow in independence Puberty Secondary school Increased risk taking Changed relationships: • experience strong pull of peer group • form new attachments i.e. dating, and • changed relationship with family
What are children aged 13-15 without disability doing?	Attend secondary school Have friends including dating Play sport social networking and attend interest based groups after school and in holidays Participate in local social and recreational activities Get together with friends on the weekend
What are children with disability aged 13-15 doing?	In families that are more stressed Developing at different rate More involved with family members Less likely to have friends Gap after school as often unable to stay alone but few organised programs for secondary school students Use specialised transport to school
Gap	Increased stress Less connected to neighbourhood peers and community Less clear vision and pathway
Expectation of specialist supports	To be goal oriented and responsive: directed to the needs and goals of individual as they change To be responsive and tailored to the needs of the individual To guide development by supporting new learning to be incorporated into everyday tasks, routines and activities providing real life learning experiences To support mainstream services so that learning is reinforced across all environments
Strategies to enhance relationships and belonging	Facilitate positive adjustment of family relationships: • assist family to develop positive vision and a pathway • assist family to respond in more adult ways • address family issues that might hinder development of relationships • encourage friendship with siblings and extended family, and • reframe ‘babysitter’ support to age appropriate support Strengthen relationships with peers and in community:

Issue	Children 13 to 15
	• strengthen social and relationship skills • identify strengths and interests as basis for relationships • broaden networks and develop social and relationship skills • support to participate in age appropriate family, cultural and religious practices • address after school support if required, and • support inclusion in local sports and interest groups
Strategies to enhance autonomy and decision making	Spend time with peers without adult moderator Support to make choices Support to take action to bring choice to fruition Support to understand consequences of actions
Strategies to promote challenge and contribution	High expectations at school and in all activities Expect child to help others Expect services/ activities to require child to do tasks appropriate to skill level

Appendix A6: Reasonable and Necessary support for children 6 to 15 and their families

Issue	Goals	Outcomes	Supports	System
Reasonable and necessary for children 6-15	To gain functional developmental and coping skills To participate in some activities without parents To be increasingly involved in decision making that affects them	Children grow in independence	Therapeutic intervention Thoughtful planning to enable increases in independence, capacity to ask for assistance, increased resilience Support to make decisions	Tier 3
			Increased participation with peers and in community	LAC, community
	To be included in your local school	Children are welcomed and educated in their local school	Learning support	Education
			Personal care and disability related support	
	To have friends to spend time with To belong to groups based on interest To be loved	Children form friendships with peers and have positive relationships with their family	Skilled facilitation to enable membership Strengthen social and relationship skills	Tier 3 LAC
			Capacity building for parents	Tier 2 (ILC)
	To participate in before and after school and vacation programs (as required) To participate in groups in the community based on interests	Children participate in local social and recreational activities	Inclusion support in community activities Inclusion support in out of school hours care	LAC state & federally funded out-of-school hours care
Vulnerabilities	To build congruence in everyday family life between needs of the child with disability and needs of other family members To strengthen integration of child with disability into their everyday family life and the community more generally	Well supported family that can care for all their children Avoidance of out-of-home placement and/or family breakdown	’Whatever it takes’ supports to facilitate a healthy well-functioning family Behaviour support for child Encourage and assist to establish use of informal care of grandparents, friends, babysitters	Tier 3

Issue	Goals	Outcomes	Supports	System
	To minimise concern about the effect of the child with disability on siblings both now and in the future			
Reasonable and necessary support for families	To support the development of peer relationships	Families support their child to develop and strengthen peer relationships	Capacity building Skill building to enhance social and relationship skills of children Skill building to facilitate connections	Tier 2 (ILC)
	To understand their child's development and how child is progressing To have positive views of their child's developmental progress and future To include their child in age appropriate traditions of the culture	Families understand their children's strengths, abilities and special needs. Families include child in extended family, culture and community	Information Support to build a positive vision and pathway Parent advocacy understandings and skills Contact with families with children with similar needs	Tier 2 (ILC)
	To advocate for services and supports for their child To identify their needs and how to access available services and supports to meet their needs To understand their rights and the rights of their child with disability	Families know their rights and advocate effectively for their children.	Information	Tier 1
			Vision building Family advocacy training and support Connection to empowering disability networks	Tier 2 (ILC)
	To make informed decisions about their child To feel confident in their parenting	Families help their children develop and learn.	Information Capacity building	Tier 2 (ILC)
	To have people to call upon for practical support	Families feel supported.	Support use of informal care of grandparents, friends, babysitters	Tier 3

Issue	Goals	Outcomes	Supports	System
	To have people to call upon for emotional support To have people to call upon to look after their child		“Whatever it takes’ supports to facilitate a healthy well functioning family Support to maintain life roles other than carer Support to maintain relationships and belonging	
	To feel confident to access services and community activities To see themselves in partnership with professionals and services To feel themselves in control in selecting services and supports that meet the needs of their child and family To view themselves as equal and integral members of the team	Families are able to gain access to desired services, programs and activities in their community	Planning process	Tier 3
			Support to negotiate with service providers and support workers	Tier 3
			Capacity building	Tier 2 (ILC)
			Professionals and services that assume capacity and work in person centred ways	Tier 2 (ILC) capacity building for services
Systemic approaches		Out of school hours services are inclusive	Support to develop and use informal care	Tier 3/LAC
		Communities are welcoming		LAC Local Govt
		Flexible work environments are responsive to the needs of parents of children with disability		Employment & Workplace Relations
		Health and education professionals have high expectations and support inclusive paths for all children		Health Education Tertiary training

Appendix A7 Key features young adults 16-25

Issue	Adolescents and young adults 16-25
Key features of life stage	Growing independence, choice, voice and control: • develop own identity, develop and pursue interests • self sufficient, and • adapting to physical and emotional changes during puberty Changed relationships: • peer pressure • form new attachments i.e. dating • become sexually active, and • changed relationship with family Thinking about the future: • gain employment, and • moving out of home
What are adolescents and young adults 16 to 25 without disability doing?	Attend and complete secondary school Attend post-secondary education and training Have friends Have intimate and sexual relationships Develop sexual and gender identity Play sport Get together with peers on the weekend and holidays Experiment – test boundaries Distance themselves from family
What are people with disability aged 16 to 25 doing?	Living a controlled and confined life built on low expectations: • Independence, choice and control: o reduced control over major decisions in life o low self esteem, and o lack of support to develop capacity in decision making • activities of daily living: o little control of daily routines of personal care, shopping paying bills, meals etc. • Relationships and belonging: o isolated, few friends, spend time with older people o not supported to develop intimate relationships, and o need for sexual expression often ignored • Home: o most live with family • Health: o psychological challenges emerge for some o key health decisions made by others, and o lack education and support to build capacity to make decisions related to health • Education/training: o struggling to complete secondary school, and o struggling to enter and complete post-secondary education

Issue	Adolescents and young adults 16-25

	and training
	- Work:
	  - less likely to have meaningful work experience
	  - less likely to be in inclusive environments - in sheltered employment and day program, and
	  - struggling to secure work
	- Social participation:
	  - less likely to be volunteering, and
	  - less likely to be with peers

Gap	Increased stress At danger of lives becoming very different from peers Increased vulnerability to exploitation including sexual abuse Less connected to neighbourhood, peers and community Poor social skills Need for information, vision and pathway
Expectation of specialist supports	To be goal oriented and responsive: directed to the needs and goals of individual as they change To be responsive and tailored to the needs of the individual To guide development by supporting new learning to be incorporated into everyday tasks, routines and activities providing real life learning experiences To support mainstream services so that learning is reinforced across all environments
Strategies to promote relationships and belonging	Identify strengths and interests as basis for relationships Broaden networks and develop social and relationship skills Relationships and sexuality education to build capacity to make decisions and reduce vulnerability to exploitation Supported opportunities in ordinary environments - education, training, work, clubs Support valued roles that promote connection
Strategies to enhance autonomy	Assist person and family to develop positive vision and pathway for a life comparable to peers without disability Opportunities to pursue choice and control in all domains of life Assist to make choices and take action to implement choice Assist individual to plan for a home of their own
Strategies to promote decision making	Strengthen supported decision making Specific focus on capacity to make decisions that reduce vulnerability to exploitation
Strategies to promote social, economic and cultural participation	Plan for and develop valued work roles and volunteering Develop internships, mentoring and strategies to build relationships with potential employers Support to take active roles in community
Strategies to	High expectations

Issue	Adolescents and young adults 16-25
promote challenge	Work Education Volunteer roles that enhance sense of competence and contribution

Appendix A8: Reasonable and Necessary support for young people 16 to 25 and their families

Issue	Goals	Outcomes	Supports	System
Reasonable & Necessary support for a good life for people 16 to 25	To become more independent seen in: • -access to relevant information • making choices and having control over major decisions in life • feeling like a capable contributing adult • opportunities to grow skills and decision making • being supported to be yourself, and • capacity to direct one's own support • to plan for the future	Individual has access to relevant information Individual has enhanced functional and coping skills Individual makes decisions or is supported to make decisions Ideas for an adult life explored and implemented within the appropriate cultural context Individual feels valued Individual directs support Individual is satisfied with his/her say in the development of the NDIS plan Individual is satisfied with his/her say in the implementation of the NDIS plan	Key focus on increased independence	Tier 3 – planning Tier 2 (ILC)
			Support with transitions – value of multi-agency planning	NDIS, education + others
			Support to build a vision, a plan, maximise potential and make decisions	Tier 2 (ILC)I Tier 3
			Infrastructure to underpin life building support	Tier 3
			Supported decision making in place in all areas of life	Tier 2 (ILC) and 3
			All supports assume potential, are person centred and support risk through safeguards	Tier 3
	To maximise independence in tasks of daily living Supports for daily living enable the achievement of goals	Individual achieves maximum possible independence in activities of daily living Assistance in activities of daily living overcomes difficulty	Support to build a vision, a plan, maximise potential and make decisions	Tier 2 (ILC) capacity building Tier 3
			Support in areas of domestic assistance, personal care, travel, communication and finance minimise difficulty	Tier 3
			Skill building	Tier 3
			All supports assume potential, are person	Tier 3

Issue	Goals	Outcomes	Supports	System
			centred and support risk through safeguards. Support to plan and implement personal safeguards	
	To develop new relationships To strengthen relationships with peers To develop more adult relationship with family To experience a sense of belonging in friendship circles, family and community To have people to call upon for practical and emotional support	Individual has friends Individual sees friends without adults present Individual feels like he/she belongs Individual gets out to socialise as much as he/she wants Individual has people to call upon for practical and emotional support Individual is supported to have safe intimate and sexual relationships if over 18 and desired	Support to build a vision, a plan, maximise potential and make decisions	Tier 2 (ILC) capacity building Tier 3
			Infrastructure to underpin life building support Skilled facilitation to establish and support membership	Tier 3
			Develop social and relationship skills	Tier 3
			Support to build informal support	Tier 3
			Provide sexuality education to build capacity to make decision to reduce vulnerability to exploitation	Tier 3
			Skill building for families to assist their family member to develop friends	Tier 2 (ILC)
	To plan and establish home in a culturally appropriate way To actively choose model of housing and support, who you live with and where you live	Individual has an active plan to have own home Individual has his/her own home Individual chooses who he/she lives with and where to live	Support to build a vision, a plan, maximise potential and make decisions	Tier 2 (ILC) capacity building Tier 3
			Infrastructure to underpin life building support	Tier 3
			Support to develop informal support	Tier 3
			Support to develop a practical plan	Tier 3
			Lifestyle support	Tier 3
			Affordable housing	Cwlth Rent

Issue	Goals	Outcomes	Supports	System
				Assistance Community housing/ private rental market
	To be in good health To have a healthy lifestyle To feel and be safe at home and in community	Developing to be able to maintain a healthy lifestyle and good health Developing to be able to make choices that support good health Individual feels and is safe at home and in community	Support to build a vision, a plan, maximise potential and make decisions Assistance to maintain a healthy lifestyle Assistance to coordinate health care needs/appointments	Health system Tier 3
	To complete secondary education To participate in post-secondary education and training	Individual is engaged in education/training that is relevant and challenging Individual completes secondary and post-secondary education and training Individual has skills for work/ volunteering	Support to build a vision, a plan, maximise potential and make decisions	Tier 2 (ILC)
			Support to build a vision, a plan, maximise potential and make decisions	Tier 2 (ILC)
			Learning support	Education
			Personal care and disability related support	Tier 3
	To work in open employment	Individual gains part time work in school holidays and after school Individual gain real work experience/internship/volunteering Individual has a job designed to fit his/her strengths and interests Individual is employed in satisfying work	Support to build a vision, a plan, maximise potential and make decisions	Tier 2 (ILC) Tier 3
			Infrastructure to underpin life building support	Tier 3
			Thoughtful planning – planning valued social roles, understanding culture of workplace	Tier 3
			Skilled facilitation	Tier 3

Issue	Goals	Outcomes	Supports	System
			Inclusion support	Tier 3 and facilitation of informal support in workplace
			Mentor, Internships	Tier 3/LAC and facilitation of informal support in workplace
			Finding and supporting work	Job Services Australia or DES
	To be engaged socially, culturally and in civil society	Individual is actively connected to peers without disability Individual has active social life Individual is engaged in leisure pursuits that are enjoyable and/or challenging Individual volunteers Individual votes (18+) Individual is a member of mainstream organisations	Support to build a vision, a plan, maximise potential and make decisions	Tier 3 LAC
			Infrastructure to underpin life building support	Tier 3
			Support to explore and pursue interests in ordinary environments	Tier 3 or LAC
			Support to build informal support	Tier 3
			'Whatever it takes' supports to facilitate a healthy well-functioning family Behaviour support Support for inclusion in local recreational activities Support to strengthen extended family and friends in their capacity to engage	State family support Tier 3 LAC
Vulnerabilities	To minimise likelihood of:	Individual achieves potential and a positive future	Infrastructure to underpin life building support	Tier 3
			Behaviour support	Tier 3

Issue	Goals	Outcomes	Supports	System
	• low expectations • onset of mental health concerns • will not be included • family unable to continue to care, and • lack of affordable housing	Individual moves out of home in a planned basis, preventing out of home care in response to crisis Family has continued capacity to care	Support for inclusion in all areas of life	LAC/local govt
			Support to strengthen networks of extended family and friends	
			Supported decision making	
				Housing
Reasonable & Necessary support for family	To plan for adult life including post school education and training, work, valued roles, included in community	Families assist their family member to transition into adulthood	Information, capacity building Support to build a vision, a plan, maximise potential and make decisions	Tier 2 (ILC), Tier 3
			'Whatever it takes' supports to facilitate a healthy well-functioning family	Tier 3
			Practical support	Tier 3
			Support the use of informal care	Tier 3/ Tier 2 (ILC)/ LAC
			Succession planning	Tier 3 /Tier 2 (ILC)
	To support the development of peer relationships	Families support their child to develop and strengthen peer relationships	Capacity building Skill building to enhance social and relationship skills of children Skill building to facilitate connections	Tier 2 (ILC)
	To advocate for services and supports for family member and family To be able to identify their needs and know how to access	Families know their rights and advocate effectively for their family member with disability	Information	ILC, Tiers 1 and 3
			Parent advocacy training	Tier 2 (ILC)
			Family advocacy support	Tier 2 (ILC)
			Connection to empowering disability networks	Tier 2 (ILC)

Issue	Goals	Outcomes	Supports	System
	available services and supports to meet their needs To understand their rights and the rights of their family member with disability			
	To have people to call on for practical assistance To have people to call on to care for their family member with disability To have people to call on for emotional support	Families feel supported	Flexible individualised support for the person with disability in regular reliable ways and for emergencies Practical assistance with caring roles Practical assistance that makes a difference to the family Support to maintain life roles other than as carer Support to maintain relationships and belonging	Tier 3
	To feel confident in their ability to access services and work with professional To feel in control in selecting services and supports that meet the needs of their child and family To work in partnership with service providers to meet the needs of their family member with disability	Families are able to gain access to desired services, programs and activities in their community	Planning process	Tier 3
			Support to negotiate with service providers and support workers	Tier 3
			Capacity building	Tier 2 (ILC)
			Professionals and services that assume capacity and work in person centred ways	Tier 2 (ILC)
	To feel confident for the future	Families enjoy health and wellbeing	‘Whatever it takes’ supports to facilitate a	Tier 3

Issue	Goals	Outcomes	Supports	System
	of their family member with disability with the NDIS To be able to work as much as they want		healthy well-functioning family	
			Information, support & vision building	Tier 2 (ILC)
			Practical support	Tier 3
			Support to develop and use informal care	Tier 3/LAC
Systemic approaches		Communities are welcoming		LAC Local government Community
		Flexible work environments are responsive to the needs of parents of people with disability		Employment & workplace relations
		Health and education professionals have high expectations and support inclusive paths for all		Health Education Tertiary training

Appendix A9 Key features of an ordinary life for adults 26-55

Issue	**Adults 26-55**
Key features of life stage	Have choice and significant control over their lives Have relationships including sexual partners, children, grandchildren and friends Have their own home Undertake post-secondary education and training Work Develop and pursue interests Provide care to elderly parent
What are people with disability doing?	Living a controlled and confined life built on low expectations: • Choice voice and control: o reduced control over major decisions in life o low self esteem, and o lack capacity to grow skills in decision making • Daily living: o little control of daily routines of personal care, shopping paying bills, meals etc. • Relationships and belonging: o isolated, few friends, fewer proportion have partners o spend time with older people o not supported to develop intimate relationships, and o need for sexual expression often ignored • Home: o younger cohort live with family, and o older cohort live in group accommodation • Health: o poorer physical and emotional health than their peers o key health decisions made by others, and o lack education and support to build capacity to make decisions related to health • Lifelong learning: o younger cohort struggling to enter and complete post-secondary education and training, and o older group disengaged • Work: o less likely to be in inclusive environments - in sheltered employment and day program, and o struggling to secure and retain work • Social participation: o less likely to be volunteering, and o less likely to be with peers More likely to participate in grouped leisure activities
Strategies to promote relationships and belonging	Broaden social networks and develop social and relationship skills Relationships and sexuality education to build capacity to make decisions and reduce vulnerability to exploitation Supported opportunities in ordinary environments - work, clubs

Issue	Adults 26-55
	Support valued roles that promote connection Support memberships of interest based groups
Strategies to enhance autonomy	Assist person and family to develop positive vision and pathway Opportunities to strengthen choice and control in all domains of life Assist person to plan for and achieve a home of their own Develop valued work roles and volunteering
Strategies to promote decision making	Strengthen supported decision making in all domains Specific focus on capacity to make decisions that reduce vulnerability to exploitation
Strategies to promote social, economic and cultural participation	Develop internships, mentoring and strategies to build relationships with potential employers Foster real adult interests
Strategies to promote challenge	Work Continuing education
Strategies to promote contribution	Expectations of contribution to others Enhance competences of role as family member Volunteering – take on roles that enhance sense of competence and contribution

Appendix A10 Reasonable and necessary support for adults 26 to 55 and the families with whom they live

Issue	Goals	Desired Outcome	Supports	System
Reasonable & Necessary support for an ordinary life for adults 26-55	To experience choice and control seen in • -access to relevant information • making choices and having control over major decisions in life • feeling like a capable contributing adult • opportunities to grow skills and decision making • being supported to be yourself, and • capacity to direct one's own support	Individual has access to relevant information Individual makes decisions or is supported to make decisions Individual is satisfied with their say in the development of the plan Individual is satisfied with their say in the implementation of the plan Individual feels valued Individual has increased capacity to direct their own supports	Support to build a vision, a plan, maximise potential and make decisions	Tier 2 (ILC) Tier 3
			Infrastructure to underpin life building support	Tier 3
			Supported decision making in place in all areas of life	Tier 2 (ILC) and 3
			All supports assume potential, are person centred and support risk through safeguards	Tier 3
	Supports for daily living enable the achievement of goals	Assistance in activities of daily living overcomes difficulty Individual achieves maximum independence in tasks of daily living	Support to build a vision, a plan, maximise potential and make decisions	Tier 2 (ILC) capacity building Tier 3
			Support in areas of domestic assistance, personal care, travel, communication and finance minimise difficulty	Tier 3
			Skill building	Tier 3
			All supports assume potential, are person	Tier 3

Issue	Goals	Desired Outcome	Supports	System
			centred and support risk through safeguards. Support to plan and implement personal safeguards	
	To develop new relationships To feel like you belong with friends, family and the community To have people to call upon for practical and emotional support	Individual is supported to maintain roles of partner, parent Individual has friends Individual has opportunity to make new friends Individual spends time with friends without a mediating person present Individual feels like he/she belongs Individual gets out to socialise as much as he/she wants Individual has people to call upon for practical and emotional support Individual is supported to have safe sexual expression and intimate relationships	Support to build a vision, a plan, maximise potential and make decisions	Tier 2 (ILC) Tier 3
			Infrastructure to underpin life building support Skilled facilitation to establish and support membership	Tier 3
			Develop social and relationship skills	Tier 3
			Support to build informal support	Tier 3
			Provide sexuality education to build capacity to make decision to reduce vulnerability to exploitation	Tier 3
	To establish a home that is culturally appropriate To actively choose the model of housing and support, who you live with and where you live	Individual has a home that is culturally normative Individual chooses who he/she lives with and where he/she lives	Support to build a vision, a plan, maximise potential and make decisions	Tier 2 (ILC) Tier 3
			Infrastructure to underpin life building support	Tier 3
			Support to develop informal support	Tier 3
			Support to develop a practical plan	Tier 3
			Lifestyle support	Tier 3

Issue	Goals	Desired Outcome	Supports	System
			Affordable housing	Cwlth Rent Assistance Community housing/ private rental market
	To be healthy To lead a healthy lifestyle To feel and be safe at home and in the community	Individual has an annual health check Individual maintains a healthy lifestyle and good health Individual is able to make choices that support good health Individual feels and is safe at home and in community	Support to build a vision, a plan, maximise potential and make decisions Assistance to maintain a healthy lifestyle Assistance to coordinate health care needs/appointments	Health system Tier 3
	To have opportunities for lifelong learning	Individual feels they are learning new things Individual is engaged in education / training that is relevant and challenging Individual completes post-secondary education and training Individual has skills for work/ volunteering	Support to build a vision, a plan, maximise potential and make decisions	Tier 2 (ILC)
			Support to make choices in education	Tier 3
			Learning support	Education
			Personal care and disability related support	Tier 3
	To work	Individual is employed in satisfying work	Support to build a vision, a plan, maximise potential and make decisions	Tier 2 (ILC) Tier 3
			Infrastructure to underpin life building support	Tier 3
			Thoughtful planning – planning valued social roles, understanding culture of workplace	Tier 3
			Skilled facilitation	Tier 3
			Inclusion support	Tier 3 and facilitation of

Issue	Goals	Desired Outcome	Supports	System
				informal support in workplace
			Mentor, Internships	Tier 3/LAC and facilitation of informal support in workplace
			Finding and supporting work	Job Services Australia or DES
	To be engaged socially, culturally and in civil society	Individual has volunteer roles Individual is engaged in leisure pursuits that are enjoyable and/or challenging Individual votes Individual is a member of mainstream organisations	Support to build a vision, a plan, maximise potential and make decisions	Tier 3 LAC
			Infrastructure to underpin life building support	Tier 3
			Support to explore and pursue interests in ordinary environments	Tier 3 or LAC
			Support to build informal support	Tier 3
Vulnerabilities	To minimise likelihood of: • low expectations • mental health concerns • not being included, and • family unable to continue to care	Significant others hold high expectations Individual experiences emotional and psychological wellbeing Individual experiences relationships and membership Individual moves out of home in a planned basis, preventing out of home care in response to crisis	Infrastructure to underpin life building support	Tier 3
			Behaviour support	Tier 3
			Support for inclusion in all areas of life	LAC/local govt
			Support to strengthen networks of extended family and friends	Tier 3
			Supported decision making	Tier 3
	Lack of affordable housing	Individual lives in affordable housing		Housing
Reasonable & Necessary	To have people to call on for practical assistance	Families have the support they need to care Families feel supported	Flexible individualised support for the person with disability in regular reliable ways and for	Tier 3

Issue	Goals	Desired Outcome	Supports	System
support for family where participant lives with family	To have people to call on to care for their family member with disability To have people to call on for emotional support		emergencies Practical assistance with caring roles Practical assistance that makes a difference to the family Support to maintain life roles other than as carer Support to maintain relationships and belonging	
	To be able to advocate for services and supports for their family member and their family To be able to identify their needs and know how to access available services and supports to meet their need To understand their rights and the rights of their family member with disability	Families know their rights and advocate effectively for their family member with disability.	Information	ILC, Tiers 1 and 3
			Parent advocacy training	Tier 2 (ILC)
			Family advocacy support	Tier 2 (ILC)
			Connection to empowering disability networks	Tier 2 (ILC)
	To feel confident in their ability to access services and work with professionals To feel themselves in control in selecting services and supports that meet the needs of their child and family To view themselves as equal	Families are able to gain access to desired services, programs, and activities in their community.	Planning process Support to negotiate with service providers and support workers	Tier 3
			Support to negotiate with service providers and support workers	Tier 3
			Capacity building	Tier 2 (ILC)
			Professionals and services that assume	Tier 2 (ILC)

Issue	Goals	Desired Outcome	Supports	System
	and integral members of the team To work in partnership with service providers to meet the needs of their family member with disability		capacity and work in person centred ways	
	To plan with family and friends about the future for their family member with disability when they are no longer the primary care givers To support their family member with disability to spend days and nights away from the immediate family	Families have succession plans	Succession planning seminars	Tier 3
			Support to strengthen informal support	Tier 2 (ILC)
			Positive opportunities for people with disability away from family including overnight	Tier 3
	To feel more confident for the future of their family member with disability To be able to work as much as they want	Families experience health and wellbeing	‘Whatever it takes’ supports to facilitate a healthy well-functioning family	Tier 3
			Information, support & vision building	Tier 2 (ILC)
			Practical support	Tier 3
Systemic approaches		Communities are welcoming		LAC/local government Community
		Flexible work environments are responsive to the needs of families of people with disability		Employment & workplace relations
		Health and education professionals have high expectations and support inclusive paths for all people		Health Education Tertiary training

Appendix A11 Key features adults 55+

Table 1: Thinking about an ordinary life

Issue	Adults 55+
Key features of life stage	Have choice and significant control over their lives Have a partners, children, grandchildren and friends Have their own home Undertake courses of interest Work Plan for retirement and retire Develop and pursue interests Travel Experience illness or disability Provide care and support to partner with illness or disability Cope with death of spouse and peers
What are people with disability doing?	Living a controlled and confined life built on low expectations: • Choice, voice and control: o reduced control over major decisions in life, and o low self esteem • Daily living: o little control of daily routines of personal care, shopping paying bills, meals etc. • Relationships and belonging: o isolated, few friends, fewer proportion are partnered o not supported to have intimate relationships, and o need for sexual expression often ignored • Home: o most live in group accommodation • Health: o deteriorating health o key health decisions made by others • Lifelong education: o unlikely to participate • Work : o less likely to be in inclusive environments - in sheltered employment and day program, and o preparing to retire • Social participation o less likely to be volunteering o less likely to be with peers, and o more likely to participate in grouped leisure activities
Strategies to promote relationships and belonging	Strengthen and maintain social networks and enhance social and relationship skills Maintain intimate relationships. Maintain capacity to make decisions that reduce vulnerability to exploitation Supported opportunities in ordinary environments - work, clubs Support valued roles that promote connection

Issue	Adults 55+
	Support memberships of interest based groups
Strategies to enhance autonomy	Assist person and family to develop positive vision and pathway Opportunities to strengthen choice and control in all domains of life Assist person to maintain their own home Develop valued volunteer roles
Strategies to promote decision making	Maintain supported decision making in all domains Focus of decision making in planning for retirement
Social, economic and cultural participation	Foster real adult interests Develop/strengthen participation in clubs and community organisations
Strategies to promote challenge	Continuing education/extending skills in areas of interest
Working toward contribution	Expectations of contribution to others Enhance competences of role as family member Volunteering – take on roles that enhance sense of competence and contribution

Appendix A12 Goals and outcomes for reasonable and necessary support for people with disability 55+

The supports outlined for people 25-55 are the same as for people 55+. The difference is that the goals and outcomes have progressed.

Issue	Goals	Outcomes
Reasonable and necessary support for an ordinary life for adults 55+	To experience choice and control seen in • - -access to relevant information • making choices and having control over major decisions in life • feeling like a capable contributing adult • opportunities to grow skills and decision making • being supported to be yourself, and • capacity to direct one's own support	Individual has access to relevant information Individual makes decisions or is supported to make decisions Individual is satisfied with their say in the development of the plan Individual is satisfied with their say in the implementation of the plan Individual feels valued Individual has increased capacity to direct their own supports
	Supports for daily living enable the achievement of goals	Assistance in activities of daily living overcomes difficulty
	To strengthen and maintain relationships To feel like you belong with friends, family and in community To have people to call on for practical and emotional support	Individual is supported to maintain roles of partner and parent Individual has friends Individual has opportunity to make new friends Individual feels like he/she belongs Individual gets out to socialise as much as he/she wants Individual has people to call upon for practical and emotional support Individual is supported to have safe sexual expression and intimate relationships
	To maintain a home that is culturally appropriate	Individual has a home that is culturally normative Individual chooses who he/she lives with and where he/she lives
	To be healthy To lead a healthy lifestyle To feel and be safe in one's home and community	Individual maintains a healthy lifestyle and good health Individual has regular reviews of health Individual is able to make choices that support good health Individual is safe in his/her home and community
	To engage in lifelong learning	Individual engages in learning in areas of interest Individual maintains skills Individual has skills for volunteering

Issue	Goals	Outcomes
	To work	Individual is employed in satisfying work Individual plans for retirement
	To be engaged socially, culturally and in civil society	Individual has volunteer roles Individual is engaged in leisure pursuits that are enjoyable and/or challenging Individual votes Individual is a member of mainstream organisations
Vulnerabilities	Deteriorating health and skills Isolation Mental health concerns	Individual has regular health checks Individual experiences emotional and psychological wellbeing Individual has relationships and membership
	Lack of affordable housing	Individual lives in affordable housing
Reasonable and necessary support for families with whom person with disability 55+ lives	To have people to call on for practical assistance To have people to call on to support their family member with disability To have people to call on for emotional support	Families have the support they need to care Families fee supported
	Where caring role is held by parents: To implement succession plans To support individual with disability to establish a sustainable home	People with disability are assisted to transition into their own home
	Where family is NOT parents: To plan with family and friends about the future for their family member with disability when they are no longer the primary care givers	Families have succession plans
	To advocate for services and supports for their family member and their family To be able to identify their needs and know how to access available services and supports to meet their needs To understand their rights and the rights of their family member with disability	Families know their rights and advocate effectively for their family member with disability.
	To feel confident in their ability to access services and work with professionals To feel themselves in control in selecting services and supports that meet the needs of their child and family	Families are able to gain access to desired services, programs, and activities in their community.

Issue	Goals	Outcomes
	To view themselves as equal and integral members of the team To work in partnership with service providers to meet the needs of their family member with disability	
	To feel confident for the future of their family member with disability To be able to work as much as they want	Families experience health and wellbeing

Appendix B Analysis of support clusters in relation to enablers of an ordinary life

It is critical to acknowledge that, consistent with the Australian Government commitment to the UNCRPD, the Commonwealth Government and the Governments of states and territories have the responsibility to remove barriers that prevent people with disability from exercising their rights as equal and valued members of the community. The NDIS and the supports identified below are just one small part of enabling an ordinary life for people with disability. The purpose of this table however is to examine the extent to which support clusters, as currently framed, facilitate enablers or an ordinary life.

What	What is required	Cluster	Positive	Challenge
Life planning	Thoughtful understanding of values and beliefs that underpin inclusion Opportunity for iterative process over time including inclusion of people who know and care about the person Investment in people and families Shift of authority to people and families Partnerships Person centred support Strategies to overcome barriers	NDIS Planning conversation NDIS preplanning work books and information sessions	Specialisation of planners will strengthen effectiveness	Depth and time frames required for life planning must compete with tight time frames required to transition participants into the NDIS NDIS planning conversation can only deal with one aspect of life planning, namely ‘tailoring support to the individual’ Anecdotal observations of variability in quality of planner
		08 004 Life/Transition Planning	An important enabler of a good life. Elements of a plan can be ‘chunked’ for work to be authorized in a goal focused way. Acknowledged need for framework for holding service providers to account for movement toward outcomes	Descriptors do not reflect the breadth of what this item covers Needs to be more clearly spelt out in the cluster description

What	What is required	Cluster	Positive	Challenge
Building a vision	Broaden views of what is possible Evidence about what leads to good outcomes Connect people to stories of 'ordinary lives' Mentored by simlilar people	Tier 2 (ILC) Disability Support Organisations (DSOs) 08 004 Life/Transition Planning	NDIS information and pre-panning sessions provide a start. Opportunity for individualized vision building helpful	Tier 2 (ILC) and DSOs do not yet exist. There are small non-recurrent initiatives funded by state and territory governments.
Building informal support of family, friends and community	Understanding of valued social roles to promote relationships that are built on interests and citizenship rather than pity. Skilled facilitation to find opportunities and guide support workers to facilitate relationships rather than provide paid friendship.	08 004 Life/Transition Planning 15 005 Individual social skills development OR 23 022 development of skills for community, social and recreational participation LAC where emphasis is on community and belonging	An important enabler of a good life. Elements of a plan can be 'chunked' for work to be authorized in a goal focused way. Is used to support time-limited transitions. Acknowledged need for framework for holding service providers to account for movement on outcomes	Descriptor does not reflect the breadth that this item covers. Specifically, 'building informal support' does not seem a 'time limited support to assist the participant, their family and carers to develop a vision for a meaningful life and plan for their changing needs and circumstances'. Greater specificity would promote the positive supports enabled by this item.
	Development and supervision of support workers to take on roles appropriate to building informal support. Development may come through attending workshops e.g. on Active Support, SRV (Social Role	Not available		There is no avenue to fund the development of staff. Knowledge and skills in assisting a participant to develop relationships is not a core skill of support workers.

What	What is required	Cluster	Positive	Challenge
	Valorisation)			
Building skills of participant	Skill analysis including breaking a skill into its component parts, identifying opportunities to practice and rewards	15 004 Individual life and personal skills development	Can be used to fund high intensity up front training with active monitoring to scale back over time and reconfigure to facilitate continued development of skills.	Skill building **may** require higher order analysis by skilled practitioner to ensure evidence-based skill building approach tailored to participant. This item enables longer-term support than would usually be anticipated by a 'training' descriptor. Skill building support around budgeting comes from cluster 08 001 - it is inconsistent that this is not included with other skill building items. None of these items allow the payment of training fees for a participant to attend a course that teaches the skill.
Overcoming barriers	Systematic analysis of barrier at the individual, family, service and societal level and development of strategies to overcome barriers in ways that facilitate citizenship	08 002 Coordination of supports LAC where barrier relates to mainstream inclusion and effort not intensive	Very important support item that provides significant infrastructure to facilitate 'ordinary lives' Provides the source of funding for facilitation, monitoring the implementation of a plan or support item against goals Assists a person to access	This item enables greater depth of analysis, skill and planning than implied in the descriptor 'coordination of supports' Descriptor does not reflect the depth of analysis, skill and planning enabled by this line item. In everyday usage in human services, the term 'coordination' implies a more superficial linking than has been built into this item

What	What is required	Cluster	Positive	Challenge
			services related to behaviours of risk e.g. drug and alcohol	
Supported decision making (SDM)	Resource and training material targeted at people with disability families and service providers Pilot in NSW found that SDM: • Can be time intensive. • Can require intensive work to build the capacity of decision makers and supporters to be 'decision ready'. • Requires flexible arrangements for supporters as 'natural' supporters may not be available or willing to take part. • Requires filters for conflicts of interest where supporters have a vested interest in the decisions being made.	Should be resources in Tier 2 (ILC) 15 009 Training in planning and plan management	Excellent resource material was developed through the Practical Design Fund. The NDIS pre-planning sessions and the planning conversation provide a unique opportunity to raise awareness and assist people to seek increased choice and control through supported decision making	Supported decision making is very new. More prominence needs to be given to it because by its very nature it requires families and services to implement it. Will require significant skill enhancement and ongoing support for changed practice for support workers and service coordinators but source of funding for this is unclear (refer skilled workforce).

What	What is required	Cluster	Positive	Challenge
	- Sometimes requires cultural shifts to be sustainable			
Health and wellbeing	Services and supports that focus on the enablers of a good life	25 000s Physical wellbeing 2700s Therapeutic supports 08 002 & 08 003 for people who are more vulnerable	08 002 & 08 003 supports health and wellbeing for people who are more vulnerable and need assistance to link and maintain service from mainstream agencies	Lack of clarity as to the basis of differentiation between disability related needs and other needs, especially or example in relation to access to Personal trainer (25 008) and training at the gym
Community inclusion	Planning Identification of interests and possible role Strategies to reduce barriers and enhance relationships Support to facilitate relationships	LAC 15 005 Individual social skills development Or 23 022development of skills for community, social and recreational participation		LAC is useful but often not sufficient
Responding to at risk behaviour	Analysis of behaviour, a plan and training for carers and others	11001 Behaviour support management plan 11004 Intensive behaviour intervention support	This cluster can be used to respond to number of at risk factors simultaneously e.g. in relation to at risk sexual practices, drug and alcohol Co-ordination of supports	

What	What is required	Cluster	Positive	Challenge
		11006 Training for carers and others in behaviour management strategies 08002 Co-ordination of supports	can be used to facilitate access to treatments in mainstream services	
Responding to unplanned events e.g. child protection/ individual protection Sole carer in hospitalMedical emergency Abandonment Psychological deterioration - A community barrier - Loss of housing	Skilled professional to analyse situation and put in place plan and strategies to meet immediate and ongoing need. Response to specific crisis will be covered by a range of clusters as well as mainstream services	08 002 Co-ordination of supports 08 003 Co-ordination of supports – higher intensity	Co-ordination of supports is always in the plan where person is vulnerable and needs infrastructure to make things happen. Higher intensity used where person is 'not settled'. People vulnerable to crises are funded for more hours on a weekly basis so that there is money available for a crisis. If insufficient, person can come back for review. Planner would touch base with the service provider on a regular basis to amend plan as required	Would be value in more detailed descriptors Anecdotal observations in the Hunter suggest variable use of Co-ordination of supports.
Becoming a	Trusted person assists the	08 002		Recognition that the process has to go

What	What is required	Cluster	Positive	Challenge
volunteer	individual to explore their interests and seek membership of a group on the basis of shared interests. Recruit and provide training and support to a member of the group to act as a mentor and soft advocate to guide success.[22]	Co-ordination of supports (developing capacity and resilience in a participant's network) OR 15 005 social skills development 08 005 Mentoring and peer support		at the pace of the individual and the group and this may be slow. Support to mentor in the group may be ongoing at a low level. Wording of 08 005 is of a very practical nature e.g. making appointments and could be better worded to describe its possibilities
Skilled workforce	Capacity to provide specific training to staff required to assist an individual	Not covered		Cannot make assumption that staff have all the knowledge and skills required.
Shared management: Supporting participant to take on responsibility for aspects of service provision e.g. for staffing	Capacity building Shared responsibility for function with planned, phased out assistance by service provider	15 009 Training in planning and plan management 26 000 Management of funding for supports	Very positive to see clear identification of training for this function	Does not provide the opportunity for shared management many participants seeking Negative message in 26 000 with 'unable to do so independently'Replace with 'who want assistance to take responsibility for' The skill building toward self-management is separated from plan management.

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[22] See http://www.afford.com.au/employment/transition-to-retirement-sp-829?videoid=nQTfe-qVpFg

What	What is required	Cluster	Positive	Challenge
				Planner described the service intermediary role as independent of financial intermediary and as transactional rather than developmental. Information for participants indicates that the service intermediary role cannot be separated from the financial intermediary role.

Reasonable and Necessary Support for Families

Introduction

Families play a central role providing young people with social and economic support. The degree to which families are capable of providing this support is one of the most important influences on a young person's health, development and wellbeing.[1]

One of the factors that influence family capacity to care is family functioning. This relates to a family's ability to interact, communicate, make decisions, solve problems and maintain relationships. Models of strong families usually describe those that are cohesive, flexible and communicate well.[2] The level of functioning within a family can be affected by changes in family circumstances, relationships between individual family members, the balance between parental employment and family life, and other stressors that may affect the home environment.[3]

Having a family member with disability is one such factor that can affect family functioning.

Evidence suggests that families, with all their flaws, tend to provide long-term support for family members with disability and, therefore, strengthening families' capacity to care will provide beneficial life opportunities of the family member with disability.

For the purpose of this paper, a contemporary notion of family is used, i.e. family is an interdependent group of people who are bound together over time by ties of mutual consent, birth or adoption, placement etc. This includes the alternate family where children are in family based out of home care. Evidence of being a family not only stems from legal status but also from a shared sense of history, shared emotional ties and from the existence of strategies for meeting the needs of individual family members and the group as a whole. In the context of people with disability and the National Disability Insurance Scheme (NDIS), families will be diverse but their commonality will emanate from their mutual efforts to include a person with disability.

The NDIS recognises the importance of families and carers. In deciding the nature and level of support for people with disability, the NDIS is required to take into account what it is reasonable to expect families to provide. In addition, the NDIS supports families through the provision of a range of assistance to reduce the impact of the disability on family functioning.

For people with disability to have a good life they need two supports from the family. They need a family that has capacity to care – that has time and emotional energy to do what is necessary. For the long-term benefit of the person with disability, that support needs to happen in a way that does not overly disadvantage other family members so that they too develop as strong capable adults with a willingness and capacity to remain connected. Secondly, people with disability need family guides, people who have a

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[1] Australian Institute of Health and Welfare, Young Australians: their health and wellbeing, Cat. No. PHE 140, 2011.

[2] D.H. Olson, & D.M. Gorall, Circumplex model of marital and family systems, in F. Walsh, (ed) "Normal family processes: growing diversity and complexity, 3rd edition, New York, Guilford, 2003 pp. 514–547.

[3] S.Silberg, *Searching for family resilience: Family Matters*, 2001, pp. 58; 52–57.

vision of an ordinary life and the knowledge and skills to break down barriers and facilitate opportunities on their behalf. Translated into support for families, this requires two forms of support – practical assistance that shares the tasks of caring and other responsibilities and vision and skill-building support to enhance the capacity of families as advocates.

This paper aims to provide guidance to the National Disability Insurance Agency (NDIA) Board (the Board) about the most effective way in which the National Disability Insurance Scheme (NDIS) can support families in order to facilitate the best possible lives for people with disability. The paper will:

- report on the impact of caring on families and explore its implication for the nature of support
- document the voice of families discussing support
- examine the concept of respite and reframe it to be more productive for both the person with disability and the family
- link support for families to the framework of reasonable and necessary support for people with disability across the lifespan, and
- make recommendations about reasonable and necessary support for families.

Evidence about families and the impact of caring

Understanding the impact of caring on families provides some guidance as to the most effective support.

The Australian Institute of Family Studies report into the nature and impact of caring for family members with disability in Australia (2008) provides a depressing picture of caring.[4] One of the key issues to emerge from the research was that carers and their families experience higher rates of mental and physical health problems than the general population. Factors found to be associated with poor mental and physical health included caring for a person with high care needs, caring for more than one person with disability, having another care role (e.g. looking after children), having one or more problems in dimensions of family functioning, and needing more support than they were currently receiving. Carers aged 18 to 50, the age when they would most likely be caring for children, had the worst mental health and vitality as well as the highest rates of depression.

A significant proportion of carers had a change in labour force participation since taking on a caring role with a large number of non-employed carers of working age expressing a desire to be in paid employment. With the reduction in employment it was not surprising that, compared to the general population, a higher proportion of families of carers suffered from greater financial hardship.

The study reported on carers' support networks, relationships, relationship breakdown and family functioning. Although most carers had access to others who could help provide support, there was a substantial minority of carers (one in five) who had no assistance from other people in caring for the person or people with disability. Other research[5] demonstrated the impact of informal care, finding that families

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[4] The Australian Institute of Family Studies, *the nature and impact of caring for family members with disability in Australia*, Research Report no. 16, 2008, http://www.aifs.gov.au/institute/pubs/resreport16/main.html accessed on 14 April 2015.

[5] Centre for Developmental Disability Studies, *Appropriate and effective models of respite care for children under 7 years and children with disability and challenging behavior or high medical support needs*, , 2004.

with strong social support networks that offered practical as well as emotional support made less use of respite care. For the majority of carers who did have support, the support provided occasionally created issues with one in five carers encountering disagreements with others about caring.

Importantly, the provision of care was not associated with dissatisfaction with carer's relationships, but it did seem to affect carer's satisfaction with the relations of their children with one another. This is consistent with research showing the negative impact of caring for a person with disability on non-disabled siblings, perhaps due to a reduction in the attention received.[6]

Conflict is an aspect of family functioning that carers most frequently raised as problematic, with one in three carers identifying this aspect as a problem. Carers of a person with a psychiatric disability were most likely to report two or more problems in family functioning, with carers of an individual with a physical disability the least likely. Poor family functioning was associated with greater care needs of the person with disability, suggesting that the level of impairment is a good proxy measure of the likely impact of caring for someone with a disability on broader family relationships.[7] Almost one in three female carers aged 50 or less had separated or divorced since they started caring, while one in seven over the age of 50 had separated or divorced since they started caring.

Llewellyn and colleagues (1996)[8] conducted research to identify factors most likely to sever the caring relationship. She investigated families' decision to seek out-of-home care for children with disability with high support needs. The findings provide important guidance for preventive support. Llewellyn found that families most likely to seek alternate care are those experiencing:

- a lack of congruence in their everyday lives between the needs of their child with disability and the needs of other family members
- a lack of integration of the child with disability into their everyday family life and the community more generally, and
- concerns about the effect of the child with disability on their siblings both now and in the future.

Implication of carer research in relation to the nature of support

1. In relation to issues of physical and mental health

There is no simple way to improve the physical and mental health of families providing care. However, there are two key observations that must be taken seriously - findings that demonstrate poorer health is associated with providing support to a person with a significant disability, and the perception that the amount of support provided is insufficient. Wellbeing research suggests that families feel supported when they have people to call upon for practical and emotional support. Further evidence from Llewellyn suggests that families in which there is congruence between the needs of a family member with disability

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[6] Higgins, D. J, Bailey, S. R, & Pearce, J. C , *Factors associated with functioning style and coping strategies of families with a child with an autism spectrum disorder. Autism*, 2005 9(2), pp. 125–137.

[7] Australian Institute of Family Studies, op cit., p. xv.

[8] Llewellyn,G, Dunn, P, Fante, M, , *Families of young children with disability and high support needs*, Report to Ageing and Disability, 1996.

and the needs of other family members, where the family member with disability is well integrated into the family's everyday life at least feel able to continue to care. The quantum of reasonable and necessary support and the activities it permits should meet both these outcomes.

2. In relation to labour force participation of carers

The fact that a large number of non-employed carers of working age expressed a desire to be in paid employment reinforces the importance of policies that support carers who want to work. Employment laws provide minimum requirements, carer recognition legislation in some states and territories provide other assistance but their impact on changing workplace practices is slow. Advocacy for greater flexibility in the workplace would assist both carers and people with disability to secure and maintain employment.

3. In relation to concern about the impact on siblings

The research demonstrating the negative impact of caring for a person with disability on non-disabled siblings is of enormous concern. For all people with disability, but especially for those with cognitive impairment, the presence of siblings can provide an important long-term safeguard. Family support must seek to strengthen, not weaken, sibling relationships. Family support should be highly flexible, enabling the family to determine its changing priorities so that support can be used in ways that a family perceives as a priority in enabling all family members to thrive.

4. In relation to informal support

Increases in informal support, including having people to call upon for practical and emotional support, improves family health and wellbeing as well as reduces the demand on formal support. Support for families should include proactive assistance to help families strengthen their informal support.

5. In relation to relationship breakdown

Strategies to reduce family conflict would lead to better outcomes for all family members. The Australian Institute of Family Studies data suggest that support services that focus on addressing relationship conflict in the first year of caring and targeting carers under the age of 50 may reduce separations and arguments between spouses.

6. In relation to prevention of out of home placement

The breakdown of family care, especially for children, has significant negative impacts on the child. Llewellyn's research indicates that intense effort must be directed to supports to build congruence in everyday lives between the needs of the child with disability and other family members and to integrate the child with disability into the everyday life of the family.[9]

Where children are already in out of home care, the alternate family should be eligible for the support outlined in this paper and the reasonable and necessary support for the child should assist the child to remain engaged with his/her birth family where this is in the child's best interests.

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[9] Llewellyn,G., Dunn, P., Fante, M., , *Families of young children with disability and high support needs*, Report to Ageing and Disability, 1996.

Observations of support from families

The following comments relating to support from families are taken from conversations with families involved in the NDIS who will remain nameless.

> *“.... When you get respite or you get support from a disability service, it is for that one child. So if you have got two kids at school, the kid with disability can be picked up and the other one can't, so that doesn't support a family at all.”*

> *“It’s not only about the person with disability in rural and remote areas; it’s also about their families, the effects on siblings for example, on relationships and single parent families.”*

Practical Design Fund projects that focused on issues for people in rural and remote areas had significant commentary around support for families. The strongest message related to the critical importance of flexibility and pragmatism in the application of rules; that common sense must trump rules and bureaucracy every time. Additional flexibility was perceived to be required because the lack of formal services can result in the unrelenting pressures on families in caring for a person with disability. People reported that a simple lack of flexibility had made life more difficult than it needed to be. Families argued strongly that they know what will make a difference and their views should be respected and supported, utilizing local capacity in innovative and impromptu ways.

Examples of the flexibility required included:

Minding the siblings

> *“A family may need to take their child with disability to a major city for a medical consultation, minding the child’s siblings becomes an issue that can be solved by a flexible package that enables a local person to be paid to perform this role.”*

Somebody to cook a meal

> *“.... We have had access to allied health services and we have had access to health but that is not actually what we need. When my daughter wakes at 2 a.m. and screams for five hours and then spends many hours screaming during the day, I have no capacity to do my housework, no capacity to do what my son needs; so sometimes what I need is housework. Maybe somebody will cook a meal for me. Respite, God help us, yes, absolutely, we need that………..Sometimes we need really simple stuff. Child-care, for example, we were accessing, three different child-care services for my daughter because the child-care services weren't able to cope with her area of disability.”*

Money to spend as they chose to support their family

> *“In Queensland we had what was called the flexible family support until the government took the "flexible" out of it and it became "family support". It provided just a basic amount of money for families to spend as they chose to support their family; not just the child with a disability, but siblings as well, so you could spend on house cleaning, whatever it took to keep the families together. And Queensland has defunded that now.”*

Implications for support

Support is much more effective when it is tailored to the specific needs and priorities of the family and when it is under their control so that it can be adjusted in response to the changing life of a family. It is important for families to feel supported in order to build a trust that the NDIS will provide reasonable and necessary support when required.

Rethinking respite

Family support has traditionally been synonymous with respite, 'a short period of relief from something difficult or unpleasant'.[10] This paradigm sets up a most unhelpful dynamic portraying people with disability as 'burdens of care'.

Respite usually has two policy goals: providing support to carers and preventing or delaying admission to residential care. It is based on the assumption that a break will deliver much needed rest and refreshment and that families will have been strengthened and ready to take on the challenges of the returning family member. Evidence suggests however that rather than strengthen families, respite may actually reinforce the necessity for such periods of respite at increasing intervals and durations. McNally, Ben-Shlomo and Newman reported 29 studies from which there was little evidence that respite interventions had either a consistent or enduring benefit on carer well being.[11]

Armstrong and Shevellar[12] argue that respite confuses need with the strategies used to meet that need. For example, no-one *needs* respite – not even parents. What they may need is rest, recovery, re-energising and inspiration. They may also need a way of hanging on to their own roles in domains of life other than caring for their family member with disability, e.g. caring for other family members, remaining in work or seeing friends. The definition of these needs as a service type, i.e. 'respite', closes off the possibility of exploring the multitude of ways that would really have met those needs.

The respite paradigm is fundamentally flawed. It meets the needs of one party at the expense of the other. The primary purpose of respite has been met by the removal of the person or by the exchange of the caregiver. However, if respite means that the person with disability is forced to be in places or doing activities that are not relevant or life enhancing, the respite may exacerbate the person's need or be damaging for the person, especially because the respite arrangement may be repeated regularly over many years. Significantly, the respite does not address the fundamental problem.

Armstrong argues that respite care changes the nature of the parent child relationship in ways that are not helpful. A broken disability service system encouraged families to present themselves as pathetic as possible in order to be 'eligible' for a particular respite service or payment.[13] This arrangement can foster and promote an unhelpful role dynamic. In the absence of informal supports, families seek increasing

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[10] Oxford dictionary definition.

[11] Armstrong, J., & Shevallar, L., *Rethinking respite* at http://www.socialrolevalorization.com/articles/armstrong/rethinking-respite.pdf.

[12] Ibid.

[13] Armstrong, J., & Shevallar, L., Rethinking respite at http://www.socialrolevalorization.com/articles/armstrong/rethinking-respite.pdf

amounts of formalised care arrangements to rescue them from difficulty. The parent sees themself as the victim of a broken disability service system and the son or daughter is identified as the 'cause of the difficulty' and becomes the burden from which the victim must be rescued.

The need for respite is based on the faulty concept of providing families with a break. Where the question is reframed to "what would it take to enable the family and the person with disability to get a life?" one can use socially valued ways of doing things to guide the response.

The response can be based on the assumptions that:

- All relationships are enhanced by time together as well as time apart.
- When children, young people and adults with disability are engaged in real life roles, families feel more supported.
- Increased informal networks are supportive for family.

Implications for support

For people with disability to thrive, it is important that all members of their family experience health and wellbeing. This will increase their capacity to care and remain connected. Family support that pits one family member against another, that meets the needs of one at the expense of another, is counterproductive. Family support must be framed as life building opportunities for a person with disability while simultaneously providing the opportunity for family members to have their own lives.

Family support as capacity building

Capacity building refers to the developmental support that helps people to think about their lives and their supports in different ways. It exposes people to:

- visions of a life included in the community
- plans to move toward the vision
- intentional strategies to bring others into one's life as a safeguard, such as through circles of support, and
- skill building to manage a budget of support resources or to help recruit, train, supervise and support one's own staff.

Most families have significant experience of the capped crisis driven service system and have not been encouraged to become more empowered, more self-sufficient or active agents in their own lives. Reasonable and necessary support must encourage and support *capacity building to build* on the generic capacity building seminars and material that should be provided in Tier 2 (now referred to as 'Information, Linkages and Capacity Building' – ILC).

The impact of capacity building on people with disability and families

Current situation	NDIS without capacity building	NDIS with capacity building
People **maximise their deficits** in an effort to get more resources allocated to them	People continue to maximise their deficits in order to maximise their resources	People know that positive lives are built on high expectations. An overstatement of deficit and need is incompatible with high expectations
People **are frightened to use their initiative** in case it reduces their eligibility or priority for government funded services and supports	People lack examples of the type of initiative that can lead to positive outcomes People do not know how to help people with disability to develop informal support (relationships with people who are not paid to be there)	People have ideas and develop confidence. They understand that paid support contributes to positive lives but understand the need to balance paid support with freely given relationships that are central to a meaningful life.
People **defer to others as the experts** on their lives	People create plans that continue to defer to service providers as the centre of expertise	People have confidence to negotiate what they want and how they want it. They exercise choice and take the level of control they feel comfortable with
People have **service plans**	NDIS planners encourage people to identify goals and then choose service providers to implement their goals. There is little focus on building an ordinary life and few plans include strategies to build informal support A key focus for families is to get as much as possible from the NDIA	People develop goals for the life they want to live and for most this translates into using NDIS resources to compliment the support provided by family and friends.
Funding is allocated to services that provide assistance to **the most needy**	Funding is used to purchase services from traditional disability service providers	People are actively choosing from a range of services and supports including mainstream and informal supports. The NDIS package assists people to build informal support
People are **dependent users** of service	People are consumers of service who have some choice but limited opportunity to avail themselves of the choice and control anticipated in the NDIS	People are active citizens, exercising choice and control, engaging in social, economic and political life.

Implications for support

It is critical that support include opportunities for capacity building to enable families to have a vision of an ordinary life and to have the knowledge and skills required to remove barriers and enhance opportunities so that the ordinary life becomes a reality. Capacity building should be available through access to Tier 2 (ILC) seminars and resources as well as provision for specific individualised strategies funded in the participant's plan.

Reasonable and necessary support for families across the lifespan

Reasonable and necessary for families is related to the age and circumstances of their family member with disability. The two issues have been linked in the Independent Advisory Council (the Council) paper *Reasonable and Necessary Support Across the Lifespan* that guides the provision of support to achieve the following outcomes:

Domain 1: Families understand the strengths, abilities and special needs of their family member.

Domain 2: Families know their rights and advocate effectively for their family member.

Domain 3: Families help their family member to develop and learn.

Domain 4: Families feel supported.

Domain 5: Families are able to gain access to desired services, programs, and activities in their community.

Domain 6: Families enjoy health and wellbeing.

Recommendations

Support for families is a critical element of building ordinary lives for people with disability. Research affirms that the degree to which families are capable of providing this support is one of the most important influences on a person's health, development and wellbeing.[14] Within the context of the NDIS, support for families is always in the context of their family member with disability. Within this frame, the Council recommends that support for families should:

1. **Be considered very flexibly**:
   Families feel supported when they have people to call on for practical and emotional support and when their family member with disability is well integrated into their everyday life. Decisions about reasonable and necessary family support should assist families to achieve both these outcomes while simultaneously taking into account the need of all family members to thrive. Once allocated, the family should be given the authority to use the supports flexibly in accordance with the changing priorities of the family.

2. **Provide 'whatever it takes' where there is heightened risk of out of home placement.**

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[14] Australian Institute of Health and Welfare, 2011, Young Australians: their health and wellbeing, Cat. No. PHE 140.

3. **Provide support and facilitation to enable families to build informal support.**

4. **Include support to enable key family members to remain in or return to work including:**

    a. stimulating life building support for the family member with disability at those times, and

    b. if desired, assistance by the LAC in negotiating increased flexibility with a workplace.

5. **Phase out any use of the term respite**
   However, ensure that it is replaced by a response that allows both the person with disability and their family to have a life. It is critically important that in removing a term that can be perceived as demeaning, we do not overlook the essence of what we are trying to achieve, i.e. supporting family resilience in families that are the primary source of support for the person with disability.

6. **Undertake additional work on respite care**
   To understand the nature of current provision and the work that is necessary to reframe the support to enable both the person with disability and the family to thrive.

7. **Include capacity building both in Tier 2 (ILC) seminars and in targeted strategies in support packages.**

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Planning to facilitate opportunities enabled under the NDIS

Introduction

Planning is a critical step in facilitating the opportunities enabled under the National Disability Insurance Scheme (NDIS; the Scheme). It is a process designed to assist participants and their families to go from clients of a state system to citizens supported to purchase reasonable and necessary support to meet their disability support needs.

A great deal is required of the planning process. It must help an individual think about their goals and aspirations and operationalise them through strategies ultimately recorded as a statement of supports. Many participants will never have been asked to think about their goals and aspirations before and their guide in this exploration will be a stranger from the National Disability Insurance Agency (NDIA).

A further constraint on the NDIS planning process is the pressure of time. Signoff on the plan is not simply about activating support for the individual. It is also about enabling the transition of funding from states and territories into the NDIS. As so many people need to make this transition, one of the outcomes reported by the Scheme is the pace of transition: the number of days to determine participant eligibility and the number of days for the approval of the plan. While these indicators reflect understandable pressures for the Scheme, they conflict with a primary concern for the best interest of the individual.

This paper will address the issue of whether the planning process as it is currently framed is the process most likely to achieve the best outcomes for both the participant and the Scheme.

The paper provides a brief overview of what we should be able to expect from a planning process, showcasing the planning approaches favoured today. All demonstrate the breadth of considerations and the shift in power relations required for good planning if people are to be supported to have the lives they choose. The paper will present an Australian planning framework that outlines a staged approach that is useful to highlight issues in the current NDIA planning process that may diminish its potency. Complexities related to planning across the lifespan will be noted, in ways that take into account considerations as a result of heritage and when planning across domains of life like compulsory school education.

The paper will conclude with recommendations to provide greater flexibility in the planning process to achieve positive outcomes for both participants and the Scheme.

Expectations of a planning process

Planning is something that everyone does around big and small decisions in their lives. Often it is triggered by change such as leaving school, wanting to get a job or leaving home. For many people with disability, the NDIS provides the first big invitation to plan.

Observations about ordinary life planning can help us to identify elements that are important when planning with people with disability. These include:

- The person “owns” the planning. It is their interests, identity, culture and aspirations that will guide what they want to achieve in their lives.
- People who know the person well may be asked for advice and ideas.
- Professionals may be contacted to seek advice.
- The person and those who know him/her well will decide what advice is taken and acted on.
- The person will decide what is important **to** them, not what is important **for** them.
- The person will decide on the priorities and the compromises that may have to be made to put the plan into action.
- The person will have much to say about how things are going and will seek further advice or make changes if things don’t turn out the way they were expected.
- The plan is the vehicle to achieve the goal; it is not a goal in itself.
- Goals will change over time.

Approaches to planning with people with disability

Person centred planning is the main framework for planning with people with disability. It seeks to build on ordinary life planning and strengthen it for vulnerable people. Person centred planning has been used for over 25 years to unlock opportunities for people to take control of their lives.

Helen Sanderson, a leader in the field describes person centred planning as:

“… A process of continual listening focused on what is important to someone now, and for the future, and acting upon this in alliance with family and friends. It is not simply a collection of new techniques to replace individual program planning. It is based on a completely different way of seeing and working with people with disability which is fundamentally about sharing power and community inclusion (Sanderson, 2000)*.”*

Person centred planning is a gateway to person centred approaches that focus on six cornerstones of:

- values and beliefs that underpin social inclusion
- investment in people and families
- a shift of authority, control and power from the system/organisation to the individual
- partnerships with people and families
- tailoring support to the person, and
- dealing with structural barriers.

The literature on person centred planning emphasizes the importance of attention to all of the six cornerstones in order to maximize the opportunity for positive outcomes. The literature is clear that the plan may have to facilitate structural change.

The practice of person centred planning has been deepened through the work on *Intentional Safeguards***,** developed by Community Living, British Columbia. Intentional Safeguards strengthen practice by incorporating a structured approach to address personal vulnerability. The approach recognises that people with disability experience enhanced vulnerability as a result of having less money, limited access to resources, fewer friends and close relationships and negative treatment by others. A safeguarding lens is applied to the planning process seeking to address issues of vulnerability in all domains of life: health, living arrangements, work or school, financial and legal situation, self-determination, social inclusion, personal identity and communication style.

As an addition to the planning process, Intentional Safeguards actively brings vulnerabilities to the fore in order to understand them and actively identify ways to address risk and reduce the impact of vulnerabilities. It involves a person centred approach to designing new safeguards to prevent or reduce the impact of negative things happening and increases the chances of positive things happening.

Roles based planning provides a further development on person centred planning, marrying 'the most beneficial components of person centred planning to the critical thought base associated with Social Role Valorisation and to best practices for improving social status, social inclusion and employment outcomes for marginalized populations (Ramsey, 2007, p. 4).'

Roles based planning is a thoughtful means of personal planning that:

- starts with the dreams and interests of each person
- ensures each person has been provided with sufficient information and direct experience to make informed decisions about their future
- applies critical thought to the manner in which each dream or interest can be pursued in ways that will help each person be seen as a valued, contributing citizen and optimise their opportunities for developing friendships
- identifies and attempts to overcome the negative impacts of societal stereotypes upon people with disability
- identifies and responds to each person's most pressing needs and barriers to success as part of the planning process, and
- shifts focus from filling time with activities to thoughtfully and thoroughly pursuing valued roles and relationships within the community.

The dominant observation of these approaches to planning is that a great deal of time and thought is required to maximize the opportunity for positive outcomes. Planning for a good life is shown to come from multiple conversations, opportunities to raise expectations, build visions, hear stories and consult with others continually.

A review of best practice planning by Parsons, Cox and Williamson (2009) identified ten themes as organising principles for the discussion of best practice. The principles are:

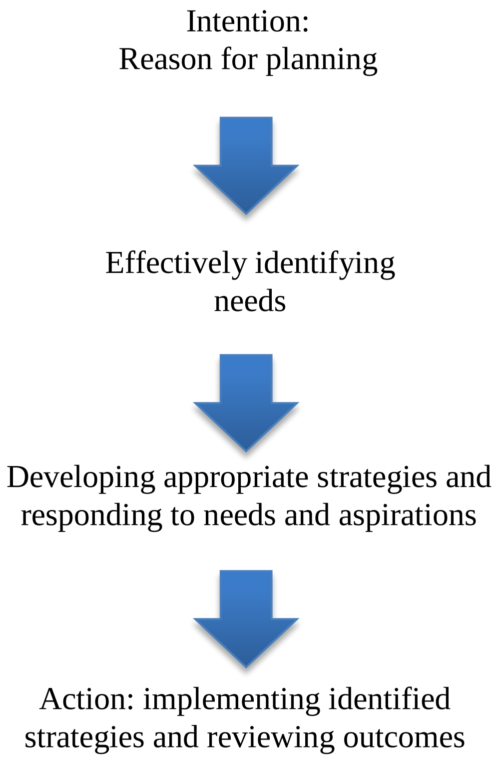
- person centred organizational culture
- listening and giving credence to what the person with disability says
- respect the natural authority of the person with disability and family

- continuity of relationship and depth of knowledge of the person
- focus on quality process and outcomes rather than tools
- identifying real needs
- a developmental process underpinned by high expectations
- safeguards
- leadership, and
- flexible approaches.

The review reinforced the view that there is no single way to plan and that the key to positive outcomes came from the depth of understanding and authenticity in relation to each of the ten themes.

The best practice review developed a *Conceptual Planning Framework* that is useful when thinking about planning in the NDIS context. The framework is based on the assumption that each element of the framework influences the next stage, paving the way to increase the likelihood that optimal outcomes will be achieved.

The framework is straightforward:



Intention

To achieve optimal outcomes from planning, the framework indicates that it is important that the planning is underpinned by the right intention.

The NDIS aims for the individual plan to initiate a process that will facilitate positive life outcomes for the person with disability – a positive and appropriate intention. However, the motivation to achieve positive life outcomes must compete with time constraints consequent to the need to transition people into the Scheme. The pressure of timing at this early point of planning may have a negative impact on the whole planning process.

Effectively identifying needs

This refers to the capacity of those engaged in planning to understand and accurately reflect the real needs and aspirations of the person. It will require considering which needs and aspirations are more important to the person and/or require more timely action. A variety of processes could be used to identify needs and aspirations. The NDIS seeks to engage the person and their support group to identify their goals and aspirations.

Experience to date confirms that many participants have never been asked to think about aspirations and hence are ill prepared for the big picture opportunities the planning could initiate.

The Agency has begun developing preplanning resources and sessions to assist people to get ready for their planning session. This is helpful but for many people is unlikely to stimulate deep thinking about fundamental needs such as the need for relationships and meaningful contribution. Such deeper understandings require a range of elements that are not yet present for many participants such as high expectations, a vision of a future different from the past and support from an informal network. Hence for many, the initial NDIA planning process at best generates ideas and commences the thinking process.

Developing appropriate strategies to respond to needs and aspirations

The literature affirms that for planning to be meaningful, it is important that the strategies developed to meet identified needs are effective, i.e. the strategies are well-matched and likely to result in meeting the needs.

Currently, NDIS plans for many participants document strategies as money to employ support workers. The strategies do not appear to include strategies or resources that would enable the direct support to actually contribute to the meeting of goals as against just maintaining the status quo.

Action - Implementing the identified strategies and reviewing outcomes

The NDIS planning process does little to activate assistance in implementing strategies. The participant is directed to a list of registered providers by state in alphabetical order and many participants are daunted to the point of inaction. The new NDIS Preplanning workbook asks participants about their level of confidence in negotiating with service providers but this anticipates limited assistance compared to the assistance needed to achieve goals. However, The NDIA will assist the participant to review outcomes when they return for a plan review.

Planning across the lifespan and in relation to particular population groups

Inherently, person centred planning responds to the individual’s life stage and heritage. When implemented authentically, the contributions, added vulnerabilities and challenges each person brings will be explored in the planning process to enable the plan to document strategies genuinely matched to the achievement of goals. In addition, if planning is to support the development of independence and build capacity, the planning process as well as the plan will need to support people to make or contribute to their own decisions and strengthen their positive vision of an independent future.

For planning to be individually relevant and potent, it will be necessary for the NDIA to develop planners as specialists. A broad based understanding supplemented by expertise of both specific disability related needs and people at different points of the life span coupled with the support of cultural guides may provide some of the strategies necessary to support effective planning. This is a big ask within the ever present time constraints.

Planning across life domains: connection with education

Anecdotal observations in the Hunter demonstrate little or no connection between NDIS planning and education for children and young people in the compulsory school years. It is understandable that many families are frustrated with their child's education and so do not invite the teacher or principal to contribute to NDIS planning. Many families feel that schools have low expectations of their child and their participation in NDIS planning will quash their dreams of an ordinary life in the post school years.

However, the opportunity for education to contribute to NDIS planning and for NDIS planning to contribute to education planning could be beneficial for the child or young person. It has the potential to share a positive vision (thereby helping the school to reframe its expectations of the student), deepen the understanding of the child or young person and support the school to plan more effectively to meet the child or young person's learning needs.

The joint contributions of school and the NDIA may activate more effective problem solving. For example, if a child is frequently absent from school related to issues of behaviour, the NDIS might activate a behaviour support assessment, a behaviour plan and some training that might reshape child and family patterns to achieve the goal of school attendance. The plan might also include some support at home to assist the family to get the child to school.

Collaboration between the NDIS and school planning could trigger plan reviews and new strategies. For example, to transition between primary and secondary school, opportunities to broaden friendship circles, subject choice, post school planning and the interplay of work experience and the casual part time jobs normative of many adolescents.

Anecdotally, none of this seems to happen at the moment, reducing the opportunity for positive outcomes.

Observations of planning and the NDIS planning

The literature review has given insights into good practice in person centred planning that highlights that there is no single way to plan and that the key to positive outcomes is depth of understanding and authenticity in relation to identified themes. One of the key observations about good planning is that it can take a great deal of time and thought with multiple conversations, opportunities to deepen understandings, raise expectations, build visions, hear stories, and consult with others frequently.

In the absence of systematic study, anecdotal information from participants, families and NDIA staff indicates that due to time constraints the planning process **may not** give sufficient focus to:

- active participation of the person with disability, especially people with limited communication
- active facilitation of the inclusion of all significant others in the planning process
- providing sufficient information and <u>experience</u> to enable informed decision making
- helping people to think about how an aspiration can be pursued in ways that help the individual be seen as a valued and contributing individual while optimising opportunities to develop friendships
- helping people think about opportunities for engagement and challenge rather than filling a week with activities, and
- identifying and strategising ways to overcome barriers to success as well as the negative impacts of stereotypes.

Anecdotally, the planning process goes well when people have thought about a vision for a meaningful life over an extended period of time or have engaged with a life planning process outside the NDIS. Participants need ideas and stimulus while being supported by friends or family, before they can conceptualise a different life. This is more than can be sought from a few conversations with an NDIS planner.

An alternate approach

The most significant constraint on the NDIS planning process comes from the time constraint of transitioning participants into the Scheme. The NDIA must identify a suitable budget that does not overstate the NDIS responsibility for reasonable and necessary support.

A small group of participants have engaged in life planning prior to the NDIS. They have developed a vision and informal support, and are clear about the quantum and role of paid support to build the life they choose. A second larger group of participants are more or less satisfied with current provision, requiring just a small supplement for equipment that must be replaced or additional support around a clear and present need.

For these two groups of people, an NDIS budget for a package of supports can be negotiated within a short time frame, which should continue to occur.

There is a third group of uncertain size: people who want significant change in their lives but lack clarity as to its nature. The alternate approach proposed by the Independent Advisory Council is for this group to receive funding to purchase support to develop a life plan. In order to transition the participant from state and territory provisions into the NDIS, a budget could be determined that covers current support and any additional support around a clear and present need plus funding to purchase support to develop a life plan. This life plan could then be brought back to the NDIA for approval to finalise an accompanying funding plan.

Scheme sustainability if people develop a life plan outside the Agency

Out-sourced planning has the potential to lead to a certain level of variability with the interpretation of reasonable and necessary, and plans could be developed that place scheme sustainability in jeopardy.

There are a number of safeguards proposed to minimise the likelihood of this occurring.

Firstly, on transition into the Scheme, participants will receive an indicative budget, an estimate of their funding package based on what they are currently receiving and the reference package developed to provide a benchmark related to type and severity of disability, trajectory of future prognosis and level of natural support. This is not dissimilar to the process in the United Kingdom where people are given an upfront anticipated budget and expected to plan within its constraints.

Secondly, participants would need to return to the Agency to sign off on the life plan.

Finally, the sustainability of the NDIS is related to costs and outcomes for individuals. It is recognised that it will take some time and significant planning for some people to move from dependent clients to active citizens living independent lives, contributing to society. It is recognised however that investment in planning and support will produce better outcomes for the individuals and eventually for the Scheme.

Ultimately, the success of independent planning and of the sustainability of the Scheme will rest on the extent to which people develop trust that reasonable and necessary support will be available when required. When Lifetime Care commenced in NSW, people made claims for as much support as they could get but as they built trust, they took what they needed because they knew they could access more when necessary.

Similarly, participants will need to develop trust that the NDIS will adjust their support if circumstances change. This may take some time to develop given that are used to a capped crisis driven system. However, the Agency will continue to have control of the size of the package that is ultimately allocated.

Recommendations

The Council recommends that:

1. The NDIA differentiate between a funding plan and a life plan:
   a funding plan being the quantum of NDIS funds allocated to provide reasonable and necessary supports; a life plan being the plan for a participant to achieve their goals and aspirations.

2. Participants can choose to:
   a. have the NDIA develop both their life and funding plans simultaneously; or
   b. elect for the NDIA to develop a funding plan based on current provision and agreed additional clear and present need as well as receive specific funding to

purchase support to develop a life plan. The life plan will be submitted to the NDIA for a funding plan.

3. The current NDIA planning process is viewed as a funding plan process in which the participant is given an indicative budget (an estimate of their funding package based on what they are currently receiving and the reference package and money for any agreed additional clear and present need) as well as specific funding to purchase support to develop a life plan.

4. The life plan is developed in an iterative process in the context of relationships with those with whom the person has ongoing connection.

5. If prepared outside the Agency, the life plan is then submitted to the NDIA for approval.

6. Life-building infrastructure and coordination are included in the funding plan as essential tools to support participants to implement their life-plans.

7. Following the determination of a reasonable and necessary funding package, the NDIA should devolve control and choice as to how the funds are spent for the individual.

8. The Agency should develop a framework to address the above.

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Promoting Independence for People with Disability

Introduction

Multiple factors in state and territory based disability service systems have encouraged and rewarded dependence rather than independence. People have been encouraged to exaggerate need to secure and retain funding and to become dependent clients rather than citizens. The capped funding has meant that service systems respond to crisis rather than implementing early intervention resulting in people with disability entering the service system at a time of heightened need and heightened dependency.

The National Disability Insurance Scheme (NDIS) provides the opportunity to reverse this negative cycle; its early intervention approach can reward capacity and initiative – people do not need to be fearful that their increased capacity and their increased independence will leave them without support. The NDIS aims to provide confidence that reasonable and necessary support will be adjusted to reflect changed circumstances.

A key question, however, is what factors impact on opportunities for independence and what should the NDIS do, in all its functions, to maximise opportunities and independence for participants. Answers to these questions have the potential to be transformative for the individual and their family and to promote sustainability for the NDIS.

This paper brings together the Independent Advisory Council's (the IAC) discussion on what independence is and what factors impact on opportunities for independence. Key research themes are summarised, followed by an outline of a growing body of literature on promoting independence in young people with disability aged 18 to 25. Implications of this literature will be drawn for adults over 25 and further writings (mainly aimed at parents) are presented to focus on independence of children and young people under 18.

The paper explores systemic barriers to independence and provides guidance as towhat independence might look like in eight life domains. The paper concludes with a discussion of the implications for reasonable and necessary support as well as Tier 2 (ILC) (ILC) resources to support independence.

Defining independence

In the context of disability, the concept of independence does not confine itself to such traditional criteria as living in one's own home, or being employed in an appropriate job. Rock (1988) argues "*Independence for young people with disability means having choice and control of their life and their environment*".[1]

The UN Convention on the Rights of People with Disability emphasises that independence for persons with disabilities encompasses:

- individual autonomy

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[1] Rock, P, Independence: What it means to six disabled people living in the community. *Disability & Society, 3(1),* 1988, pp. 27-35.

- the opportunity to be actively involved in decision making processes, and
- the opportunity to access the physical, social, economic and cultural environment.[2]

Building on the UN definition, if the NDIS is to enable and assist people to achieve individual autonomy, it must assist people to develop their own identity and maximise their self-reliance and self-direction. The goal of independence requires that people have access to the same opportunities in their physical, social, economic and cultural environment as their peers without disability and they must be supported to have meaningful choices and make meaningful decisions about the management of their life.

However, the term independence for people with disability often conjures up visions of being 'fiercely independent', of valiant efforts to achieve self-reliance with loneliness and isolation as the result. One of the basic needs of all people is to be valued and loved and 'fierce independence' seems to counter this need. In fact, relationships with people who care about (not necessarily care for) an individual provide the most significant safeguard for a vulnerable person.

Due to this, this paper argues that independence, achieving autonomy, making decisions about one's life and engagement in one's community is best achieved in equal valued partnership with others, i.e. as interdependence.

Key themes in literature on independence

Contemporary literature reflects on the changing nature of independence as family structures change and the increasing need for individuals to take responsibility for decisions in relation to actions over which they have little control.

Three themes emerge from the literature around factors impacting opportunities for independence:

1. identity development
2. resources and support, and
3. Attitudes.

The stories people tell reveals how people shape their identity and these stories are made possible by the networks to which they belong. Whilst young people with disability have the same hopes and aspirations as their peers without disability, they have less opportunity to develop social networks and this inhibits the development of identity and independence. Identity making is strongly linked to opportunities for meaningful decision-making but young people with disability have been shown to 'lack voice' in decisions about their lives.

A number of studies identify family support (attitudes and material resources) as the single most important contributor to a young person being able to maximise independence and transition into adulthood. The general attitudes of society however continue to be a barrier to independence whereby stereotypical assumptions and low expectations make people with disability feel invisible, not respected and excluded.

Independence in young people 18 to 25

A recent literature review from the University of Melbourne *"Young People with a Disability: Independence and Opportunity"* by Stokes, Turnbull and Wyn (2013) provides an excellent

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[2] Rock, P, op. cit.

synopsis of research directed to the question of what factors impact on the opportunities for independence for young people with disability.

Changing social context for young people today

Bauman (2001) and Beck and Beck-Gernsheim (2002)[3] identify the changing meaning of independence as family structures change and life course becomes de-standardised. They highlight the need for individuals to take personal responsibility for decisions in relation to actions over which they have little control. Young people have little choice but to learn how to live with new realities such as labour market unpredictability and the fragmentation of traditional pathways through education and work. Studies document the trend for young people to rely on family resources (social and material) until they are well into their twenties and are forced to make decisions about things over which they have very little choice.[4]

Three themes emerge in regard to the research question: What are the important factors that impact on opportunities for independence for young people with disability? These themes are identity development, resources and supports and attitudes.

Identity development

A traditional psychological approach describes the period form 18-25 as emerging adulthood, where different directions are possible and young people undertake character development necessary for the transition to adulthood and the acceptance of responsibility.

Other theorists (Kehily and Nayak, 2008) argue instead that identity development has become a task rather than a ‘given’; growing up is about ‘becoming’ rather than ‘finding’ a fixed (or adult) identity. The implications of this are that in a changing and unpredictable world, young people need to develop identities that enable them to negotiate their own pathways. From this perspective, the task of maintaining and re-developing identity is ongoing, and not limited to particular life phases.

Social relations

Research reveals how the work that young people do to shape identities is revealed in the narratives or stories they construct, and are made possible by the social networks to which they belong (Stokes 2012). Wierenga (2009) notes that young people’s stories reflect the worlds to which they have been exposed and in which they have already engaged. While identity formation is an individual task, identity is made possible through social relations.[5]

Yueng, Passmore and Packer (2008) conducted a study of nine young adults with cerebral palsy to ascertain their views about citizenship.[6] Whilst they were living in the community, they faced isolation and loneliness as a result of having limited social networks. Yueng and colleagues noted that it takes a long time to develop social relationships and that a young person might have to engage in an activity many times before they were recognised by others and social interactions began to occur. It was noted that opportunities to form social networks were often mediated and dependent on paid carers who may be more informed of duty of care than promoting social interaction. They stressed that simply having people in their lives (for example, paid carers) does not equate to having social networks and friendships.

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[3] Bauman, Z., (2001) *The Individualised Society*, Cambridge Polity and Beck, U., & Beck-Gernsheim, E., (2002) *Individualisation*, Sage, London.

[4] Woodman, D., (2009) “The mysterious case of the pervasive choice biography: Ulrich Beck. Structure/agency, and the middling state of theory in the sociology of youth, Journal of Youth Studies, 12 (3) pp. 243-256.

[5] Wierenga, A., (2009) Young people making a life, Basingstoke, Palgrave/McMillan

[6] Yueng, H., Passmore, A., and Packer, T (2008) Active citizenship or passive recipients: How young Australians with cerebral palsy define citizenship, Journal of Intellectual and Developmental Disability, 33(1) pp. 65-75.

The 2003 study conducted by D'Eath and Walls of young people with intellectual disability in Ireland highlights the important part that social relationships play in the process of identity development. They found that during the process of transition to adulthood, friendships and peer relationships provide support in the task of adjusting to new environments. Friendships and peer relationships also function as a mirror, helping adolescents to gauge how others see them and assist in development of self-identity. These relationships are also important as they assist in negotiating other relationships by establishing norms of behaviour, while providing a sounding board for exploring values and aspirations.

Engagement with peers and friendships support young people in their developmental processes. Peer relationships are critical for the development of independence but literature suggests that a shortage of opportunities for social interaction (compounded by lack of transport and lack of autonomy) rather than a lack of desire to participate, distinguishes young people with disability from their peers without disability. This is consistent with other research that demonstrates that young people with disability have the same hopes and aspirations as their peers without disability in term of accessing more training and education, making a lot of money, accessing sports and hobbies and having a long term relationship or marriage.

In summary, research emphasises that young people with disability have less opportunity than young people without disability to develop social networks and have less opportunity to develop stories or narratives of themselves that draw on a wide range of resources and social interactions. Their reduced opportunities are compounded by the fact that much of their social interaction is mediated by a third person, usually a support person or family member. So while young people with disability need more time to develop meaningful relationships, they have less opportunity to do so.

Decision-making

Identity development is linked to opportunities for meaningful decision-making. In particular, young people need to have capacity to embrace decision-making (choice) and accept responsibility for building their own futures. Studies examining the role of young people with disability in decision-making process about their lives highlight their 'lack of voice', that they are not properly acknowledged or involved at crucial points in the journeys to adulthood.

Studies by Stokes, Stokes and Tyler and Yueng identify what it takes to facilitate young people's involvement in decision-making. Stokes and Tyler (2001) found that young people without disability needed about four sessions with an advisor to build up enough trust to start talking about possible futures. Yueng et al (2008) found that young people with disability needed more time to develop social relationships than their peers without disability. It follows that they may need more time to build the trust required to enable them to access resources that will assist them to make good decisions about their futures.

Managing risk

Risk taking is seen as a developmental hallmark of typical adolescent behaviour. Ponton (1997) argues that risk behaviours can have benefits because they are associated with the development of independence and survival without the benefit of parental protection. It can also be argued that risk taking behaviour can help foster independence in adolescence and is viewed as assisting in identity formation.[7]

Sociological frameworks tend to focus on the conditions that place young people at risk emphasising the direct association between a young person's level of social support and the number of health

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[7] Le Breton, D., (2004) Risk taking behaviours among young people, Bulletin de l'Academie Nationale de Medicine, 188(8) pp. 1313-1321.

risk factors they exhibit. Correspondingly, studies show that young people with disability are more likely to engage in risk taking behaviour.

The literature reveals that families face a dilemma in deciding what is an acceptable risk but in order to make informed decisions, young people with disability (like their peers without disability) need to be able to make mistakes to learn. This finding highlights the need for information and support to assist families and young people with disability to make informed decisions.

Resources and supports

For young people with disability, family support is the single most important contributor to a young person being able to maximise independence and transition successfully to adulthood. Dyke, Leonard and Bourke (2007) argue that of all predictors of success, having parents involved in all aspects of the transition process and experience is critical. They state an obvious correlation between the young person's success in achieving transition to adulthood and parents who are supportive, encouraging, strong advocates and have clear expectations of their child's abilities.[8]

Socio-economic factors impact on possibilities for choice for all young people including those with disability, especially at points of transition. The fact that many parents have to give up employment when their child leaves school can have profound implications for the family and the person with disability. A recent Australian Institute of Health and Welfare (2009) study of carers highlights finance, service provision, workforce participation, stress and burden as significant and ongoing issues. Many carers reported difficulty in meeting everyday costs of living, needing to meet additional costs associated with caring, having restricted income earning capacity because of caring responsibilities and having greater difficulty in balancing caring and workforce participation.[9]

Pascall and Hendy (2004) and Dyke, Leonard and Bourke (2007) acknowledge that the most independent people are generally those with parents in higher socioeconomic strata whose parents had 'skills, time and money'. They found what they called 'unusual conditions' underpinning these young people's move to independent living including having received compensation payments, having socially advantaged and professional parents with knowledge of networks and negotiation, and having parents who had prior experience of disability.

Attitudes

Families find themselves in multiple binds as they attempt to steer their children toward independence. Dilemmas include:

- wanting to create opportunities for the young person while seeking to ensure safety
- wanting to ensure the young person has a good life while wanting their own separate life
- wanting to ensure the young person has a separate and fulfilling social life while being less involved in the social life themselves, and
- wanting to maximise their child's potential accepting them for who they are.

Studies of family attitudes to sexuality demonstrate parent's anxiety over their child's sexuality often leading to overprotection and inhibiting independence.

Whilst some studies demonstrate positive attitudes and community inclusion of people with disability, negative attitudes have persisted and have been ranked as one of the most commonly

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[8] Dyke, P., Leonard, H., & Bourke, J., (2007) Issues paper related to ARACY workshop: Leaving school: Maximising participation and life outcomes in youth with intellectual disability transitioning from secondary school to adult life, reported in reported in Stokes, H., Turnball, M., & Wyn, J., (2003)

[9] Australian Institute of Health and Welfare (2009b) Carer National Data Repository Scoping Study Final Report Canberra: AIHW.

mentioned external barriers to participation. Yueng (2008) also found that stereotypic assumptions, low expectations and misunderstandings about particular impairments impacted on young people.

Mirfin-Veitch (2003) emphasises the destructive role of low expectations in the classroom that adversely influences the child's performance and self-esteem. Lewis et al (2007) note the stress and discomfort felt by many young people with disability at having the distinction of being 'special' of 'different' reinforced insensitively.

In summary, the literature reveals that attitudes in school, workplaces and the community continue to be a barrier to inclusiveness, promotion of independence and opportunity for people with disability.

Literature from other cohorts

Adults older than 25

For adults older than 25, one can infer most of the findings of the literature still hold. For many, the role of parents will have diminished, either because the parents are tired and/or no longer present. The role of services in promoting independence becomes even more important and incentives to promote independence must be explored.

Children and young people

The seeds of independence in adulthood must be sewn at the earliest age. Where family, teachers and peers give messages of individual identity and capacity, a child or young person will come to see him or herself in a positive light, conducive to independence.

Literature about promoting independence and self-determination in children focuses on assisting the child to express choice, identify preferences, have some sense of control over their environment and a sense of autonomy in the own live. Some examples of self-determination in early childhood are choosing playmates, where to create a block tower, or getting napkins from the drawer to help set the table for dinner.

For children with disability, acquiring skills related to self-determination and independence is especially important. As their freedom to move around, express themselves clearly or interact with others may look different than what other children typically do. The challenge for families is to avoid overprotecting a child or preventing the child from taking even small risks, leading to a sense of helplessness and dependence rather than self-reliance.

There are few studies in this area but literature aimed at parents encourages independence, recognising that many children with disability are sheltered from taking risks. Parents are told that and take responsibility for the decisions and choices they make.

In order to promote independence, parents are encouraged to enable children to make choices in as many areas of their life as they can. Factors seen as facilitating independence include having reliable information, a good self-image, some personal privacy and space, having the freedom to make mistakes and having the support of other people. Other factors include being able to initiate requests for assistance from people who are paid to provide care and having aids and gadgets that enable the child to do things without help.

In addition, age appropriate opportunities to develop friendships and networks, take risks (supported by safeguards), spend time away from family and be supported to interact with others away from parents and paid people will contribute to identity formation and age appropriate independence.

Considerations for people with additional vulnerability (ATSI, CALD, rural and remote)

People with additional vulnerability include Aboriginal and Torres Strait Islander (ATSI) people, individuals from a Culturally and Linguistically Diverse backgrounds, and people from rural and remote areas. See discussion in *Reasonable and Necessary Support across the Lifespan: An Ordinary Life for People with Disability* paper.

Systemic barriers to independence

Whilst the service and education systems talk about promoting independence, there are many practices in early intervention, in disability services and schools that promote dependence rather independence. Old style early intervention often left parents with the unspoken message that children learn best in one to one interaction with a skilled adult. The value of environmental learning from peers, from interaction with family and from free play was underplayed. It led many parents to seek wrap around support (from teachers' aides) in early childhood settings and in school. Whilst this is not the case in contemporary practice, parent anxieties often turn into a demand for full time support that gets in the way of forming relationships with peers and moves to independence.

The vast majority of schools, both regular and special schools, have a tendency to attach staff to students creating learned helplessness, dependence and thwarting the development of natural networks of helpful friends. Whilst some students do need significant support, it must be crafted very carefully in order to facilitate opportunities for other children to interact and assist where necessary. Enabling children with disability to learn to appropriately ask their friend or classmate for assistance is a skill of independence that cannot be acquired if adults surround a child.

Disability services also provide support in ways that promote dependence. The much sought after individualised funding is too often used as a paid friend with whom a child, young person or adult can share an outing. Whilst pleasant at the time, paid friendship promotes dependence and only creates the demand for another slot of paid friendship. Where support workers are guided by expert facilitation and trained to understand their role as life facilitators rather than paid friends, their efforts are much more likely to lead to opportunities for relationships with community members and a sense of belonging. This has been referred to elsewhere as 'technical support' and is a necessary underpinning to enable individualised support to promote independence rather than dependence.

Service models that group people with disability significantly impede independence. Group homes and day programs have developed under the guise that people with disability are better off with 'their own' and because limited imagination anticipated that all support had to come from paid workers. Research affirms better quality of life without necessarily additional cost occurs when paid support is used to compliment informal support of family and friends to enable even people with high support needs to live in their own homes and enjoy valued roles in the community. What is often not recognised in funding formulae is that many people with disability do not easily form relationships with people who want to play a role in their lives and so investment in the development of informal support is required in order to enable this type of lifestyle.

The attitude of services to risk has a major impact on opportunities for independence. Fear of work health and safety claims have led services to avoid risk rather than mitigate risk through prudent planning and safeguarding. Ordinary activities of life become constrained as common sense gives way to restrictive processes robbing people of ordinary opportunities for a rich life.

There are many societal barriers that impede independence. Most people think of disability as a tragedy and whilst almost everyone would avoid its challenges, this attitude has a profound impact on the relationship others extend to a person with disability in ways that are often not helpful for a full and independent life. These attitudes create a view of people with disability as dependent clients who need to be cared for rather than citizens who want the same basic things as everyone else and may need some assistance in order to contribute. It turns the unique role and authority of parents into a status of carers that confuses people who deeply love and care about a person with people who are paid to provide service (and often do not care a great deal).

Compounded by poverty, these attitudes reinforce low expectations of people with disability that too often lead to the self-fulfilling prophesy of lives deprived of meaning and contribution.

Finally, and most fundamentally, where people are not exposed to different ways of doing, to different ways of living, they are deprived of opportunities to see that despite significant disability, people can lead independent valued lives included in their communities.

What might independence look like?

Many people with disability, especially people with high support needs are forced into grouped models of service provision on the basis of cost. These equations seldom take account of the cost to the individual and society of increased dependence and poor quality of life, neither do they consider the high cost of maintaining capital associated with many grouped models.

Optimal independence occurs when people are included in community, using paid support to complement informal support provided by family and friends. Optimal independence is about inclusion.

In order to promote maximum independence, it is recommended that discussion about reasonable and necessary support encourage movement along the continuum of maximising independence in all life domains. Vision building will often be important, as will deliberate strategies to build informal support, asa life surrounded by paid people is unlikely to yield the richness and independence sought and is also likely to be beyond the capacity of the NDIS to sustain.

NDIS planners will need to be proactive in opening conversations that participants may not have had. For a significant proportion of people, support to become more independent will require upfront capacity building and continual mentoring. It will also require planners to brainstorm with people the potential barriers to further independence and strategies to overcome those barriers, including adjustments to current arrangements to facilitate greater independence. The need for intentional strategies cannot be underestimated.

Finally, services delivering supports must take active steps to promote independence including through the adoption of evidence based approaches such as ‘Active Support’.

In summary, assisting participants to move toward independence requires:

- An encouraging, enabling approach that inspires people to try, supports and rewards their efforts and provides a pathway, not a prescription or a punishment.
- A recognition that asking and encouraging will often not suffice. Participants need assistance to identify adjustments required, including adjustments to the expectations of others and to the way in which support is usually delivered to facilitate greater independence. If independence was easily achieved, in most situations the participant would already be independent in the specified domain of life.
- A recognition of the critical role of peers in promoting identity and providing role models for greater independence. The development of relationships with people without disability may be a necessary first step to increase expectations and provide age appropriate guidance.

- A recognition that too much paid support may inhibit the development of freely given relationships with ordinary people. Participants and their families may require targeted support to develop informal support.
- Identification of possible ways in which technology may facilitate less dependence on paid support.
- Supported opportunities for risk taking – supporting the participant to move gently beyond his/her comfort zone to facilitate a learning opportunity from a challenge. Much work may be needed with family and service providers to facilitate an opening in which a challenge may be possible.
- The implementation of conscious strategies such as Active Support in grouped living environments. This requires staff to provide the right amount of assistance to enable service users to successfully take part in meaningful activities and social relationships irrespective of the degree of their intellectual and physical impairments. This approach means that a person might only take part in some parts of a task; they do not have to do it all or do it independently to be involved.

Table 1: Independence in Major Life Domains

Domain	**Independence measure**	**Strategies to promote independence**
Choice and control	Identity formation	Recognise and respect multiple identities of each individual e.g. encourage people to see themselves, for example, as a young woman, a member of a choir, a beach lover, not just a person with disability
	Decision making	Actively encourage the use of a framework for supported decision making such as the Victorian 7 principles (Vic. DHS 2012) of: 1. I have the right to make decisions 2. I can make decisions 3. I might sometimes need help to make decisions 4. I might be able to make decisions about some things but not others 5. I can learn from trying things out 6. I might want to change my mind 7. I might make decisions others might not agree with Encourage and support people to make daily life decisions – when to get up, go out, where to go In planning meetings, take steps to enable people to make big

Domain	Independence measure	Strategies to promote independence
		life decisions e.g. where they live, what work they do, the services they use
	Self determination (have authority and are supported to direct and manage their own services)	Help people to take steps to move along a continuum from: Other people direct and manage the services for the individual Learning to manage and direct their own services Supported to manage and direct their own services Able to manage and direct their own services
Daily life	Increasing skills toward self sufficiency	Provide training to facilitate increased skill Provide support to decrease reliance on paid support
	Active choices around nature of assistance	Support people to make the adjustments required to choose who assists them, how they are assisted, when they are assisted and where they are assisted
	Travel without support on public transport	Provide travel training to assist use of public transport
Relationships	Existence of relationships with people outside family and paid staff	Support people to make the adjustments required to go out as an individual (not in groups) and to attend places at regular times to facilitate being known and valued
	Choice of relationships	Support people to choose who they have relationships with, how often they have contact with people and assistance to extend relationships if desired
	Pursue relationships in ways and frequency of choice	Support people to have contact when they choose and in ways that they choose
	Independence in interaction	Support people to spend time with a friend without staff or family being present
	Engage in safe sex	Provide people with training and support in sexual health

Domain	**Independence measure**	**Strategies to promote independence**
Home	Choice of home	Support people to actively choose the model of housing and support and who they live with and to actively plan to achieve this goal
	Control over support in the home	Support people to make the adjustments required to have control over who supports them, how they are supported, when they are supported and where they are supported, including when they get up and go to bed, what they eat, when they go out, with whom and where
Health and wellbeing	Self-reliant in coordination of health related supports	Support people to take steps toward understanding the screening and services they need for good health and assist them to make and keep appointments and implement recommendations from appointments
	Self-reliant in maintaining a healthy lifestyle	Support people to take steps toward understanding elements of healthy lifestyle and making adjustments required for a healthy lifestyle
Education and training	Participation in course of choice	Support people to choose and be supported in a mainstream course rather than a course for people with disability Support people to choose and be supported in a course in their area of interest
Work and valued social roles	Nature of employment or valued social role	Support people to choose and be supported in: - open employment over sheltered employment, and - valued social roles that demonstrate competence in the area of their choice
Social, community and civic participation	Nature of leisure activities	Support people to genuinely choose (as against from a menu of options) leisure interests and activities, including time and location, and their leisure partners
	Engagement in mainstream community groups	Support people to become actively involved community groups that reflect their interests Support people to actively participate in community discussion about issues of interest.
	Voting	Support people to understand the electoral system, to register

Domain	Independence measure	Strategies to promote independence
		and to vote

Conclusion

The NDIS provides new incentives for people with disability to move from the status of dependent users of service to that of citizens who are independent and exercise choice and control. The United Nations Convention on the Rights of Persons with Disabilities' (UNCRPD) understanding of independence is an inclusive one encompassing individual autonomy, the opportunity to be actively involved in decision making and the opportunity to access the physical, social, economic and cultural environment. NDIS plans and supports need to be framed to assist participants to move in these directions.

The literature review highlighted key strategies that promote independence: assisting people to develop their identities, supporting people to make decisions and strengthening families to build positive visions that guide toward independence. The research reveals that young people with disability have the same aspirations as their peers without disability but have less opportunity to develop and participate in social networks that will guide the development of their identities: a key to independence. In addition, their 'lack of voice' in decisions about their lives is a critical barrier to the development of independence and an important area for action. Finally, a number of studies have found family support to be the single most important contributor to a young person being able to maximise independence and transition into adulthood: the challenge becomes supporting more families to provide the vision and support required.

The unique nature of each person's impairment combined with the unique nature of his or her environment means that independence will be unique to each individual. This cannot be left, however, as an excuse to leave people as dependent service users who are bystanders in their own lives. It is in everyone's interest to promote maximum independence for each person with disability; it will provide the best opportunity for the individual to have a good life, it will provide the best opportunity for their family to feel proud and connected and it will provide the best opportunity for the NDIS to be sustainable.

The way forward

Conscious strategies are required to reshape the low expectations and conscious and unconscious societal devaluation that push people with disability into dependence rather than independence. The NDIS alone cannot tackle these issues but its paradigm shift opens new opportunities to change attitudes.

Recommendations

The following recommendations are made in relation to **reasonable and necessary** support to promote independence for each and every person with disability and participant.

1. Apply the ordinary life test in assisting a person plan their life

People with disability have the same aspirations as people without disability. The NDIS provides reasonable and necessary support to work toward the achievement of those aspirations. Therefore, in every situation, NDIS planners must help the individual to move toward enhanced independence by addressing the age appropriate level of autonomy, decision-making and economic, social and cultural contribution that one would expect of their peers who do not have a disability.

2. Take active step to reduce barriers

Effective planning must anticipate barriers to the achievement of a goal and develop strategies to overcome the barriers related to the negative impacts of societal stereotypes as well as the specific barriers related to identifying goals. Failure to do so will leave plans as dreams rather than practical steps to achieve dreams, and may exacerbate low expectations and low self-esteem.

3. Recognise the critical importance of relationships

NDIS support needs to focus on the development of relationships as a priority. Friendship is a critical concern for most people and research has confirmed the importance of peers in the development of identity.

The tension between independence and reliance on others is difficult for many people with disability. However, being supported to be active agents in their relationships and having maximum control over the what, when, where and who supports them reinforces a person's decision making and identity and strengthens their autonomy.

Some people may need reasonable and necessary support to gain the skill base that is helpful to build and sustain relationships. For others reasonable and necessary support may be required to consciously bring others in to a circle of friendship or support.

For services, knowing, respecting valuing and understanding what is important to people may mean prioritising things differently at a service level, such as helping people and support workers to put into practice core skills involved in making and keeping friends.

4. Provide 'technical assistance' as part of the reasonable and necessary support

Often direct support creates and strengthens dependence rather than independence. Expert facilitation is critical in order to assist paid staff to facilitate the development of relationships rather than just provide paid friendship. Technical assistance may also be required to enable children, young people and adults with disability to interact with others away from the mediation of family and/or paid staff and to attain membership rather than remain peripheral attenders.

5. Move toward independence in social, economic and cultural participation, in daily living and in home

Table 1 provides a guide to independence in major life domains. The truism that each person (with and without disability) is unique cannot be used as a justification to leave people with disability as dependent clients. NDIS reasonable and necessary support and the services that implement it have a responsibility to help people move along a continuum toward increased independence. Table 1 aims to provide some guidance as to what independence might look like in domains of life.

6. Ensure people are supported to make decisions

Decision-making is a vital skill in supporting self-determination. Assistance to increase skills in making decisions is a critical feature of NDIS planning and support.

7. Promote opportunities for risk-taking in an enabling and safeguarded way

Every planning conversation must include a sensitive and thought provoking discussion of possible risks and what safeguards can be put in place to mitigate those risks. Literature affirms the importance of risk taking for the development of confidence and independence, therefore safeguarded risk taking is an essential part of reasonable and necessary support.

8. Educate people with disability and families

Planning conversations and the shape of reasonable and necessary support must assist people to understand the importance of independence. It must provide vision building opportunities and link people to role models that help them understand what independence might look like for a similar person.

9. **Encourage the use of more independent, less restrictive models of service provision**

For independence to feature as a priority for participants of the NDIS, planners will need to alert people to alternate approaches and support people to move beyond the constraints of traditional grouped services.

For this to be available for people with high support needs, reasonable and necessary support will have to be able to be deployed flexibly to compliment informal support provided by family and friends. With careful planning and deliberate strategies to build informal support, people with high support needs can use the unit cost of shared living to live in their own homes with a combination of paid and informal support.

Capacity building in relation to independence

Reasonable and necessary support must be underpinned by initiatives in Tier 2 (ILC) that build the capacity of people with disability, families and services to support independence. This includes:

1. Vision building activities that shares stories and gives life to the meaning of, for example, independence and real lives of people with high and complex needs;
2. Specific vision building activities for parents of children and young people to demonstrate the value of independence, how to promote it and how to develop safeguards to mitigate their concerns.
3. Peer support to guide people on the journey to greater independence and citizenship. This is valuable for children and young people as well as adults.
4. Training and resources around supported decision-making so that families and service providers build skills in ensuring that children, young people and adults with disability are involved and supported to make decisions.
5. Training and resources for people with disability, families and services on risk enablement and safeguarding that invigorates the dignity of risk and the opportunity to learn from mistakes.
6. Provide incentives for services to promote independence in participants.

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Promoting Self-Direction[1] in the National Disability Insurance Scheme

Introduction

The National Disability Insurance Scheme (NDIS) provides a unique opportunity for people with disability in Australia to have the support they need to live the lives they choose. A number of core elements differentiate the NDIS from state and territory schemes. First, eligible individuals are able to identify personal goals and aspirations and receive reasonable and necessary supports to complement informal, community and mainstream services. Second, the funding is allocated to the participant to support independence and social and economic participation and to enable the exercise of choice and control to the full extent of the participant's capacity. Self-directed funding that gives participants control over major decisions related to the nature and delivery of their support is a critical element in making the legislative aspirations a reality.

Architects of the NDIS understood the value of self-directed funding and support drawing on the evidence of its association with improved health and wellbeing. A significant body of research consistently reports that self-directed funding and support is associated with greater satisfaction levels, perceptions of greater power and control over life decisions, improvements in quality of life, spending time with people, taking part in the community, feeling safe and secure at home, personal dignity, economic wellbeing, increased social networks and the perception of improved quality of supports.

The research quoted by the Productivity Commission in Appendix E of its report *Disability Care and Support*[2] draws on studies with different management arrangements facilitating self-direction. Differences are related to variations on two critical issues: **who holds the funds** and associated administrative arrangements and **who controls the funds** through planning and managing the package. Some studies reported on direct payment and the majority reported on mechanisms in which a service provider shared control with the individual. Positive impacts of self-direction are consistent irrespective of whether the individual manages the funding or the responsibilities are shared with a service provider.

In fact, the beneficial impacts of self-direction are reported by the Productivity Commission to extend to the service system. These include reducing the demand for formal services, costing less than other alternatives and partly addressing staffing shortages.

Research demonstrates that people with self-directed support have more active social networks, increased social, economic and community participation and improved wellbeing. These factors are also associated with less dependence on the formal service system. The Productivity Commission

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[1] This paper deliberately uses the term self-direction rather than self-managed in order to convey a broader application of choice and control as seen in the glossary in Table 1

[2] Productivity Commission Report *Disability Care and Support*, August 2011, Appendix E.

argued that there is enough evidence from diverse sources to suggest that self-directed funding is likely to be less costly than alternative service models.[3]

The Productivity Commission also argued that self-directed funding and personal planning may partly address the shortage of staff because it will draw the so-called 'grey' market of family, friends and neighbours into the pool of people who can provide support to people; it will reduce the number of administrators responsible for contracting and managing frontline workers by shifting that responsibility to people with disability and their families and it will shift away from specialist services to mainstream services (for example, joining a local scouts group or a gym).

The Independent Advisory Council (the Council) believes that the NDIS unnecessarily limits the recognition and support for self-direction thereby reducing positive impacts for individuals as well as the NDIS. The Council believes that the NDIS definition of the term self-management is unnecessarily narrow and fails to recognise and support the multiple systems and services mechanisms across Australia that enable people with disability and families to have significant control over the way they manage their supports.

This paper will outline barriers to self-direction drawing on first-hand experience of people with disability, families and services in the Hunter as people transition into the NDIS. These barriers include the lack of clarity of language, limitations of plan management provisions of the NDIS, unintentional disincentives to self-management and prevailing attitudes that self-management is 'too hard'.

The paper will then outline enablers of self-direction including recognition of state and territory shared management options, recognition of and support for quality plan implementation support, incentives to retain and strengthen the positive aspects of self-direction and strategies to assist people to self-direct. A proposal for adjustments to the current plan management approach will be outlined to provide clear messages to enable and support people with disability to direct their own support.

Experience of Hunter residents moving from the NSW self-managed Community Participation program to the NDIS

The New South Wales (NSW) self-managed *Community Participation* program provides day program support for young people with a disability with moderate to high support needs who need an alternative to paid employment or further education in the medium or longer term.

The program operates under a shared management approach where a service provider is the fund holder and participants and their parents are able to negotiate the level of responsibility they want in relation to planning, staffing, support coordination and financial management. The funding from NSW includes 12 per cent for service and financial administration costs.

Self-managed *Community Participation* has been available in NSW since 2009 and a significant group of the early adopters now undertake all the life planning, staffing and support coordination functions. Some participants enjoy the control self-managed Community Participation gives them

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[3] Productivity Commission Report *Disability Care and Support*, August 2011, p.E.5.

over lifestyle decisions, but prefer to retain the quality plan management support. Others continue to look to the service for assistance in staff recruitment and training, support coordination and the life planning required for moving from aspirational goals to real life outcomes.

Feedback from some people who have moved from self-managed *Community Participation* to the NDIS in the Hunter Trial Site suggests that they are not satisfied with the transition. The main reason appears to be the perception that the NDIA only pays for direct support and makes no active provision for aspects of service provision they relied upon in shared management such as:

- life planning from aspirational goals to the micro-steps required to achieve an outcome
- capacity to select staff individually
- support coordination, and
- professional development of staff.

In theory, an NDIS registered plan management provider could undertake some of these functions as part of its service intermediary role. However, given that no participants have used a plan management provider, it can be deduced that this avenue of sourcing supports has not been accessed.

There is a fear that if the value of life planning, assistance with staffing, and support coordination are not recognized and funded, the functions will not be there in the future.

Most people with disability and families in the Hunter trial site have not been aware that these are services they need to request. They believe they are asking for the 'self-managed *Community Participation*' under the NDIS and that the professional assistance they have taken for granted will be part of the package. When they realise it is not, they are faced with uncomfortable conversations with service providers who inform them that coordination supports need to be written into the plan, or that additional money will not be provided to advertise to replace staff if they leave.

Case study

> *The family of a gentleman with autism believed that his 23 hours of direct support per week had been transferred from a NSW self-managed funding program to the NDIS. He remained with the same provider but experienced a most significant change, namely that instead of being able to select his own staff when his staff moved on, he was forced to use allocated agency staff and over a period of months went from having 3 staff to 9 staff. In addition, he was forced to change the times at which he received assistance to fit in with staff timetables.*

Case study

> *The mother of a young woman with very high and complex needs has found that the flexibility she and her daughter valued so highly has reduced. Previous lifestyle choices such as having a massage and support to attend a concert in Sydney (requiring an overnight stay) are now not permitted. Under state provision, the young woman had a budget determined by her support needs and she was free to use it as appropriate. This has been replaced by the payment of direct support for NDIA approved line items significantly reducing the person centred nature and flexibility of her support and lifestyle.*

> *Issues around staffing are also of great concern. The requirement to use the agency staff when her staff leave has been exacerbated by the fact that one highly trained support worker that the family selected and trained is now no longer available to them because she is being used by 'people in greater need'. The mother reported that she feels she has lost the anchor she experienced through the supportive relationship with the service especially the 'sounding out' conversation that she valued. She is not sure where that type of support will come from in the future.*
>
> *Finally, the mother reported that there was no real discussion about plan management. She undertook to self-manage a small part of her daughter's package and the NDIA planner assumed that the Agency would manage the rest.*

Anecdotal evidence suggests that where people have been primed to ask for coordination, they have only been successful where they can argue their needs are complex for which they have received 10 hours per year for this assistance. This provides less assistance than they have been used to.

These case studies reflect a serious reduction in self-direction. The capacity to select staff is central to having a lifestyle of choice; especially for people with cognitive impairment for whom paid support has the capacity to facilitate valued roles and lifestyle. Only staff that truly know the person and are committed to their goals will promote relationships in ways that fade out the role of paid staff.

Barriers to self-direction

Confusion of language

The term 'self-management' is not used consistently across Australia and this is causing confusion for people with disability, families, service providers and government. The term is not defined in the glossary of the NDIS *Quarterly Reports* but operationally, it refers to individuals who directly receive all or part of their funding and are responsible for all aspects of implementation and reporting of their NDIS package. Limiting the definition in this way does not represent the intent of self-management as it suggests that individuals who choose to have varying involvement with the administrative processes are not taking control of their lives, their supports and their funding.

The following table lists the terms associated with self-management and defines their current usage within Australia.

Table 1 Terms and definitions associated with individual funding in Australia

Term	**Common usage**	**Use in other contexts**
Self-directed support	An approach that gives people with disability greater control over their support and their lives. Often described as self-directed planning, self-directed funding and self-directed support. Self-directed support can be managed through a service provider, a financial intermediary or via a direct payment. Most of the literature on self-directed support refers to arrangements in which a service provider is the fund holder (i.e. shared management)	Consistent meaning across jurisdictions.
Self-managed	Self-managed 'support' is used in NSW to describe arrangements whereby a service provider holds the funds and the participant takes the desired level of responsibility for life planning, recruitment, training and support of staff, and for support coordination. Service provider is the employer.	Self-managed 'funding' is used by the NDIS to refer to payment of the entire package directly to the participant (or nominee) who is responsible for all aspects of administration of the package.
Direct payment	States and territories use this term to refer to an arrangement whereby the payment of the entire package is made directly to the participant (or nominee) who is responsible for all aspects of administration of the package.	NDIS refers to this as self-managed funding.
Shared management	Agreed sharing of funding and service management responsibilities between the person with disability and their family and a disability service provider who holds the funds. The participant takes the desired level of responsibility for micro planning, recruitment, training and support of staff, for support coordination and in some states for employment and payment of staff.	In NSW this is referred to as self-management. Some of these functions are undertaken by a plan management provider under the NDIS
Plan management	NDIS term defined as 'managing the funding for supports in a plan' and includes purchasing the supports, receiving and managing funding from NDIA and acquitting funding provided by NDIA.	No known usage of this term nationally.

Limitations of NDIS plan management

The *NDIS (Plan Management) Rules and Operational Guidelines* deal with issues of management of funding under the plan.

Information sheets for participants identify plan management options (self-managed, registered plan management provider, the NDIA or a combination) and describe a registered plan management provider as an individual or organisation that manages the funding of support in a participant's plan. The role of a service intermediary is introduced and includes:

- assisting participants develop skills in this area
- negotiating and coordinating the provision of supports
- sourcing providers
- negotiating method and timing of delivery of supports, and
- negotiating individual requirements as part of the support management.

The service intermediary role can only be undertaken in conjunction with the financial intermediary role.

There are a number of significant limitations of the NDIS plan management framework. Firstly, many people are confused about the concept of plan management. To most people with disability, a plan consists of much more than the money. The plan is the document linking aspirations with supports to achieve outcomes and people want to own the plan as a symbol of ownership of their lives. Conversely, the term 'plan management' suggests that the participant's aspirations and lifestyle are being 'managed' and this is contrary to the philosophy that the NDIS provides participants with the opportunity to learn how to take increasing control of their packages and their lives.

Secondly, the Council believes that the assistance anticipated in the service intermediary role is not an optional extra if an individual is to move from having a paid friend to using paid support in ways that complement and extend informal support. It appears that most NDIS participants are currently funded for direct support but without the infrastructure of a service intermediary role, most participants will not maximise their opportunities.

Thirdly, the service intermediary role as described by the NDIS may be too limited. Under shared management, favoured by many under state and territory programs, the service intermediary provides quality plan implementation support, assisting participants with life planning involved in moving from aspirational goals to implementation of outcomes. Examples of this include having friends, having a job, moving into a house, staff recruitment, training and coordination support, as well as employment and payment of staff.

For most participants, these functions are undertaken in a capacity building manner that leads to an increased readiness to take responsibility. However, some participants seek ongoing service involvement and choose the shared management option for the authority it affords in choosing lifestyle and ensuring supports are implemented to achieve outcomes in ways consistent with NDIS values.

Finally, the fact that the service intermediary role is not identified in the *Rules or Operational Guidelines* and can only be undertaken in conjunction with the financial intermediary role has led it to be little understood, and consequently not utilised. One provider described this linking as a fatal flaw for the service intermediary role.

Table 1.3.1 of the *NDIS Quarterly Report to the Council of Australian Governments (COAG) Disability Reform Council (March 2014)* demonstrates that the option of using a plan management provider under the NDIS is not understood. Across the trial sites, the majority of plans are agency managed. Only a small proportion of plans are solely self-managed and no participants are using a plan management provider.

State	Agency Managed	Combination	Plan Management Provider	Self-Managed
NSW	68%	30%	0%	2%
SA	83%	12%	0%	5%
TAS	66%	31%	0%	3%
VIC	71%	29%	0%	1%
Average	**72%**	**26%**	**0%**	**2%**

In summary, the Council believes that under current NDIS plan management processes, the valued assistance found in state and territory shared management has been lost. This represents a loss of technical assistance critical to building the capacity of people with disability and families to maximise the opportunities enabled under the NDIS and a loss of recognition and valuing of options to attain self-direction.

Disincentives to self-manage under the NDIS

There is no reward to the individual (other than control over their supports) for taking on the additional responsibilities related to self-management. For example, in NSW, eligible people receive a package of support based on their assessed need. The size of the package is based on the cost of gaining the required support with a service provider taking 12 per cent for administration. Where a person uses a financial intermediary (at a cost of 5 per cent of their package), the person gains the benefit of being able to use additional hours of support from their package. Where a person uses self-management, further additional hours of support accrue to the individual.

Under the NDIS, this incentive of extra value for money does not accrue to the individual. The Agency argues that people are allocated reasonable and necessary supports and that it would be inequitable to advantage people who take the additional responsibilities of self-management. This reflects a disincentive when compared to current state and territory service systems.

In addition, the NDIS fee structure does not sufficiently differentiate service offerings of ‘technical’ assistance that people value under shared management. This includes offerings such as additional time for life planning, support to recruit, select, train and supervise staff and support coordination. If the fee structure differentiated these offerings, more people would be interested to purchase assistance with self and shared management, making the task easier.

The prevailing view that self-direction is too hard

The uptake of self-directed services in the United Kingdom (UK) varied enormously, more than could be accounted for by chance. Analysis indicated that differences in the attitudes and support given by local authorities, varying animosity from public sector unions, and variations in voluntary sector advocacy for direct payments significantly affected the adoption of consumer-directed payments (Hasler and Stewart 2004, Rankin 2005, Riddell et al. 2005, Glasby and Littlechild 2009, pp. 47ff, Davey et al. 2007, reported in Glasby 2007).

This is reflected in a recent Australian study by Rees (2013) where study participants believed it was critical to challenge the attitudes of funding bodies and organisations that place barriers that inhibit the take up of self-management. This means stopping the prevailing message that self-directing or self-managing is ‘too hard’ and something to be feared.

Enablers of self-direction

Recognition of, and support for, shared management as an option with which people are familiar

State and territory systems have used shared management structures for many years. The service provider is the fund holder and employer of staff, and responsibilities for aspects of service management are delegated to people with disability and families reflective of their capacities and wishes at any time. The intermediary roles are highly valued, providing ‘technical assistance’ which is crucial in assisting people to increase their capacity to direct their own support. They have provided a training ground for people who want to self-manage their funding.

Other participants want the service provider to retain a role but choose the shared management option because they want to ensure that the support is used to develop the chosen lifestyle in ways that are consistent with family values. Offerings provided through self-management and NDIA managed services do not afford participants this level of choice over management for service delivery.

Recognition of, and support for quality plan implementation support

Effective service provision under shared management offers participants much more than direct support. Services provide quality plan implementation support, helping people to plan, develop skills and orient staff to enable the direct support to go from an outing with a paid friend to facilitation of opportunities to develop relationships, build informal support and remove the paid support aspect. This is not the natural orientation of direct support workers and if direct support is the only aspect of service provision funded, opportunities inherent in individualised support will be missed.

Many people who use disability supports to complement informal support have gained the knowledge and skills to do so from quality plan implementation support provided by skilled and experienced people.

More recent participants who have not had the experience of shared management models may not recognise the need to seek this professional assistance and will then flounder in moving toward their real life goals.

Quality plan implementation support leads to more cost effective support because it produces the development of informal support that can improve both quality of life (because it leads to an increase in real relationships) and reduce the amount of paid support over time. Quality plan implementation support needs to be recognised and funded by the NDIA as a standard part of service delivery.

Retain and strengthen the benefits of state enabled self-directed support

Strengthen the person centred nature of NDIS plans and supports

Many individuals and families consider the reduction in flexibility as a shortfall that is directly related to the NDIS attempting to fit participants' lifestyle choices into prescribed fields. The Council believes it is important to provide maximum flexibility in how people use their reasonable and necessary support, as long as the requirements of value for money and not duplicating the supports available from other systems are met.

For example, when an adult with disability chooses to use funding to pay the rent for house sharers who provide significant informal support, the Council believes that the Agency should recognise the use as value for money rather than preventing the practice on the general provision that rent is a private expense. The Agency should consider that this particular example is one of an innovative use of support funding - the participant pays his own rent from personal income but uses his reasonable and necessary support to pay (or subsidise) the rent of the house sharers as a strategy to establish a home living with friends who do not have a disability in a way that is cost effective.

For example, when an individual with significant physical disability uses their funding to purchase a massage, the Council believes that the Agency should recognise this as a value for money approach to health and wellbeing that reduces muscle tension and the likelihood of decreased mobility. The fact that people without disability pay for a massage from personal income is not the issue.

Retain and strengthen capacity for participants to select their own staff

Service providers in the Hunter have argued that the unit cost of service provision is insufficient to enable people to advertise for their own staff. Certainly, people who have been prevented from recruiting and selecting their own staff (after moving from shared management in NSW to the NDIS) relate this directly to the unit cost from the NDIA compared to the unit cost from the NSW government.

The capacity to select staff is an aspect of self-direction most valued by participants who are prepared to take considerable time and effort to ensure a good fit with the person assisted. NDIA facilitation of opportunities for participants to be able to select their own staff will provide a very strong incentive to the uptake of self-direction.

Assist people with disability and families to direct their own support

The move to self-directed support must come from the individual. The NDIA can, however, set in place strategies under which moves to self-direction are more likely to occur. Some strategies include:

Provide clear information to assist people to use self-directed and self-managed options

This should be achieved by:

- offering training
- developing online resources, and
- developing a telephone advice line that provides information necessary for the smooth and successful management of a support package, e.g. wage rates, insurance, and occupational health and safety information.

Build the capacity of individuals

Rees (2013) asked people who were self-managing their packages (i.e. had a direct payment) what type of assistance they believed would be valuable in assisting others think about self-management. They identified factors critical to success including:

- proactive thinking about what a good life might look like, including assistance to develop a vision and strengthen informal support
- the opportunity to connect with others who are self-managing, and
- having clear information about what self-management entails, including from personal, financial and administrative perspectives.

The NDIS needs provide incentives for skill development, particularly for participants using self-managed and self-directed options. The availability of systemic strategies that build capacity of people with disability and families (tier 2, now referred to as ILC) as well as enabling individual participants to have capacity building funds within their package (tier 3) would be of value.

Facilitate the development of user-led organisations that supports people to self-manage

Glasby and Duffy (2007) reported that where direct payments have been taken up enthusiastically, the biggest successes have often come where there is a user-led ‘Centre for Independent Living’ to provide advice and peer support for people thinking about such an option and starting to test out whether it is for them. Steps should be taken to encourage the development of user-led, Disability Support Organisations as obvious sources of peer support.

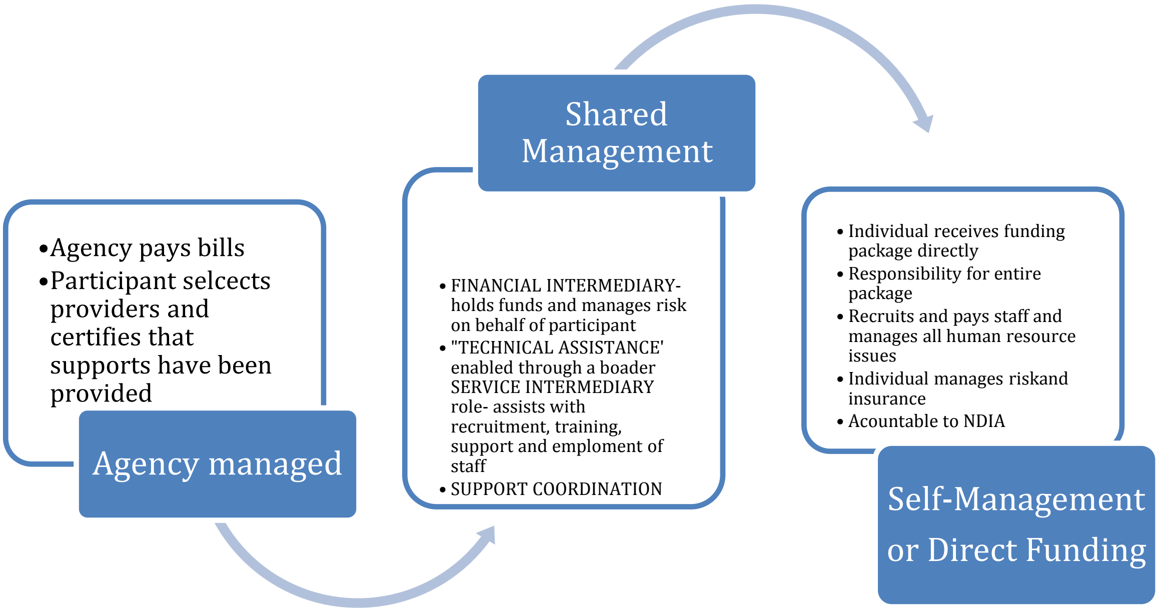
Embed supports for people who face multiple disadvantages

It could be argued that use of shared management is an option that affords increased flexibility, and so accommodates individual circumstances for people of Aboriginal and Torres Strait Islander (ATSI) and Culturally andLinguisticaly Diverse (CALD) heritage and people in rural and remote areas. This is because shared management gives people the opportunity to develop a lifestyle and support that is very individual and therefore more closely aligned to their values, cultural practices and lived experience. However, the challenge is that few people experiencing multiple disadvantages use self-directed options because they lack the knowledge and skills to negotiate the system.

Additional targeted assistance will be required if people experiencing multiple disadvantages are to have greater uptake of self-directed options. It is anticipated that such steps would increase participant engagement and satisfaction with the NDIS as well as increase the empowerment of participants. Experience in self-directed options could provide a stepping-stone to the use of self-management.

Alternative framework describing the continuum of self-management

The limitations of the NDIS plan management framework could be overcome by either replacing the role of the plan management provider with that of shared management, or ensuring that the functions of shared management are fully incorporated in the role of the registered plan management provider. Shared management is a term understood by people with disability, families, service providers and governments across Australia and more clearly delineates the roles and responsibilities intended. The use of the term as part of the articulated functions in planned management would be an advantage. Further work to develop the continuum of self-management, including exact functions and their appropriate fees, would be beneficial.



- Agency pays bills
- Participant selcects providers and certifies that supports have been provided

- FINANCIAL INTERMEDIARY- holds funds and manages risk on behalf of participant
- "TECHNICAL ASSISTANCE' enabled through a boader SERVICE INTERMEDIARY role- assists with recruitment, training, support and emploment of staff
- SUPPORT COORDINATION

- Individual receives funding package directly
- Responsibility for entire package
- Recruits and pays staff and manages all human resource issues
- Individual manages riskand insurance
- Acountable to NDIA

Recommendations

1. **Develop a glossary to assist people across Australia to discuss the issues around individual funding**

The states have been delivering a variety of individual funding models and have developed their own terminology and definitions. The development of a national glossary is essential and will facilitate the inclusion of valued options from states and territories as well as comparisons between the NDIA experience and international experience.

The Council recommends that the Agency work with state and territory governments to develop a glossary.

2. **Clarify plan management options to either:**
    a. **incorporate shared management functions into registered plan management providers, or**
    b. **replace the concept of registered plan management providers with the concept of shared management.**

The role of plan management providers has not been understood and the fact that the service intermediary role can only be undertaken in conjunction with the financial intermediary role has inhibited its use. In addition, the service intermediary role as currently structured does not appear to provide the depth of assistance provided in share management options.

Clarification on the way to proceed is a critical decision for the Council on this issue. In any case, it is essential that any barriers to its utilisation be removed.

3. **Collect statistics on participants using shared management/plan management providers in the cohort of participants who self direct under the NDIS.**

The current NDIS measure of people self-managing their plan is taken as a symbol of the extent to which the NDIS is facilitating choice and control. The level of choice and control anticipated to result from the revision to the responsibilities in **recommendation 2** means that these participants should also be recognised for the independence and self-direction they will demonstrate.

4. **Strengthen the enablers of? self-direction through the following actions:**
    a. **Recognise and support quality plan implementation support**

Quality plan implementation support that provides skilled advice and facilitation for life planning, staffing, and the development of role and support coordination is a critical part of individualised service provision aiding direct support to go from an outing with a paid friend to the facilitation of opportunities to develop relationships, build informal support and eventually remove paid support.

The Council recommends that quality plan implementation support is viewed as an essential element of support and built in individual packages.

    b. **Retain and strengthen the state enabled benefits of self-directed support including:**
        i. **Strengthening flexibility**

The Council acknowledges the improvement in flexibility that will result from the bundling of supports. However, some of the flexibility enabled under state provision has been lost as a result of having individuals' lifestyle choices filtered through an NDIS assessment.

The Council recommends a re-examination of the state enabled options that are prohibited under the NDIS (e.g. a personal trainer, a massage, payment of rent for a house sharer) and enable them if they represent value for money.

ii. Strengthening capacity for participants to select their own staff

The capacity for participants to select their own staff is an aspect of self-direction most valued by participants. It is considered essential if participants are to develop valued roles and informal support.

The Council recommends participants who are not using their support in a grouped environment be enabled to select their own staff.

iii. Assisting people with disability and families to direct their own support

The move for participants to self-direct support must come from the individual. However, the Agency can also establish strategies to maximise the likelihood that participants will want to self-direct.

The Council recommends that clear information is provided about self-directed options including challenging the view that self-direction and self-management is too hard, that resources are devoted to build the capacity of individuals to direct their own support (through allocations in their packages as well as through ILC funding, and that steps are taken to facilitate the development of user-led organisations, which is associated with increased uptake of self-directed options in the UK).

5. Implementing the recommendations in one trial site

The Council is mindful of the significance of recommendations that alter the infrastructure of the NDIS. In the context of a learning environment, it is considered sound to implement on a small scale and review impacts and outcomes prior to wider implementation.

The Council recommends that the recommendations of this report are trialled in one of the total population launch sites.

6. Cultural change around the concept of 'registered plan management providers'

The Council recommends that concept of 'registered plan management providers' as contained in the *National Disability Insurance Scheme Act 2013*, be culturally changed to reflect the roles and responsibilities found in state and territory 'shared management' providers (for example, through the operational guidelines, engagement and other explanatory material).

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Implementing the NDIS for people with disabilities related to mental health

Contents

Executive Summary

Purpose

In late 2013, the Independent Advisory Council (IAC) for the National Disability Insurance Scheme (NDIS) identified the issue of improving the Scheme's responsiveness to people with psychiatric conditions as a priority for its work in 2014. Over the past 12 months, the IAC has undertaken considerable work in listening to the views of consumers and family/ carer advocates and the mental health sector, building an understanding of how the trial sites are responding to applicants and participants with disability arising from mental health issues. Conclusions and directions outlined in this Report were also informed by the findings of a concurrent Literature Review "Mental Health and the NDIS" (August 2014). On this basis, the IAC has been considering the conclusions and directions outlined in this report and the operational and definitional issues in delivering the NDIS objectives and deliberating on possible options for improving the Scheme's responsiveness to people with disabilities associated with mental illness.

The IAC has considered these issues throughout its meetings in 2014. This report represents the outcome of those deliberations and was approved by the IAC at its December 2014 meeting.

Background

The inclusion into the NDIS of people with disabilities related to mental health issues occurred after the initial Scheme design. The mental health sector has been supportive of the inclusion of people living with a severe and persistent mental illness into the Scheme but has also advocated for further refinements to improve its responsiveness and strengthen participation. The National Disability Insurance Agency (the Agency) has been aware from its commencement, of the need to address some specific requirements and issues in relation to people with primary and secondary disabilities related to mental illness.

There have been a number of forums and discussions between the Agency and Mental Health Australia (MHA) and mental health service providers interested in the Scheme at national and trial site levels. The Board asked the IAC to give consideration to this issue, and subsequently the IAC has focused in its work plan on developing a better understanding the particular needs of participants who are eligible for the NDIS due to disability associated with mental illness. A range of initiatives have been commenced within the Agency to identify areas for improvement and build engagement with the mental health sector. In May 2014, the Agency appointed Eddie Bartnik as a mental health adviser to the Scheme. In addition, Mental Health Australia (MHA) was given a sector development grant to address policy and practice development issues.

There is now sufficient trend data and information emerging from the trial sites to give some indications as to how the Scheme is responding to people with a mental illness. In its first 15 months of operation, 1,114 people with a disability related to mental illness have been found eligible for support. Of these, 752 participants recorded a mental illness as their primary disability and 362 with mental illness as their secondary disability. Most of these participants come from NSW and Victoria and are aged from 35 to 64 years of age.

Data from the trail sites indicates that ineligibility rates from access requests from people with primary mental illness that are significantly higher than other disability types with 1:4 applications requesting access due to primary mental illness being determined as ineligible compared to 1:9 for applicants across the rest of the Scheme.

The number of participants with disabilities related to mental illness in the Scheme to date is lower than projected by the Productivity Commission, and there is a need to understand the reasons for these trends. The data from the first 15 months of operation highlights the centrality of the issues raised in this report for the future of the Scheme.

While it is still early in the Scheme’s implementation, and more detailed analysis is required, this report has found that those who are eligible are receiving additional levels of support and there appears to be reasonable levels of satisfaction with the operation of the Scheme. The fundamentals of the Scheme appear to be sound for people with disability associated with a mental illness but some refinement is required to maximise the Scheme’s potential and minimise some risks that the Scheme is exposed to at this point. A major risk identified by the Council is that lack of national consistency across the trial sites in the assessment of severe and permanent disability due to mental illness and the determination of reasonable and necessary resources. The operating guidelines, funding items and Agency practices need to be tweaked and adjusted to improve NDIS responsiveness to the needs of people with disabilities associated with mental illness.

This report identifies a number of emerging issues that require more concerted attention by the Agency. It proposes that the adoption of an ‘NDIS Mental Health Implementation Plan’ would facilitate the Scheme reaching its full potential for people with disability associated with mental illness. This report offers ways forward for the Board and the Agency to address these issues and mitigate the risks associated with lack of attention to these matters.

There is enormous good will at Board, Agency, State and Territory Government levels, at Mental Health Australia and within the mental health sector to make the Scheme work as well as it can for people with disability arising from mental illness. Changes required are achievable within the current legislative and financial settings for the Scheme but will require concerted action and investment over the next five years. The changes required address definitional and operational issues and be readily addressed with clear and timely actions.

Recommendations

The IAC recommends that the Board considers the development of a five-year ‘NDIS Mental Health Implementation Plan’ as a statement of its directions and priorities in improving the Scheme’s responsiveness to people with disabilities related to mental illness.

It also recommends that the Board and the IAC are provided with an annual report card in October each year, concerning progress towards achieving the goals as set out in the implementation plan.

Committing to such a plan would assist the Agency to address these issues in a strategic focused and timely manner over the next five years.

The report identifies a number of key issues that the IAC recommends need consideration in the ‘NDIS Mental Health Implementation Plan’ and the proposed strategies to address these issues. This Executive Summary highlights five of these, which are outlined in the table below. These and other key issues, as well as proposed recommendations for each, are discussed in detail later in the report.

Issues and proposed responses

ISSUE	**PROPOSED RESPONSES**
Definitions and guidelines on what constitutes severe and permanent disability related to mental illness Ineligibility rates for applicants with a mental illness are significantly higher than those resulting from applications from people with physical, intellectual and sensory disabilities. The reasons for this are unclear and need further investigation. Within the trial sites there is no consistent evidence base behind determinations or around the current definitions of severe, persistent and episodic disabilities for people with disabilities related to mental illness, and application appears to vary across state jurisdictions. This forecasts significant risk and predicts that the Agency may be subject to higher rates of appeal unless a consistent and evidence-informed approach is applied to the determination of severe and persistent impairment. The Agency must develop a position on determining permanency that encompasses ‘episodic’ and functional impairment as well as indicating ‘reasonable and necessary’ supports as a matter of urgency.	NDIA should build on-going capacity within the Agency to develop its own evidence-based working definition and guidelines on severity, permanency and episodic nature of disabilities related to mental health issues. NDIA to establish a specialist mental health/ psychosocial disability team at the NDIS Head Office with deep understanding of disability and expertise in assessment of eligibility, reasonable and necessary supports and support planning and review for people with disabilities related to mental illness as well as mental illness and other disabilities, in particular intellectual disability and autism. This team to be led by a person with significant experience in both disability and community-based mental health service delivery. It is envisaged that a

ISSUE	PROPOSED RESPONSES
	team of three to four people would be required to oversee and undertake the scope of activity. This work would be in addition to the work of the specialist adviser on mental health, Eddie Bartnik. This team to lead the work focusing on policy, guidelines, quality and practice development in regard to the Agency's definition of permanence of disability related to mental health issues and provision of training, tools development and support, and advice on assessment of eligibility .
Building a nationally consistent approach to reasonable and necessary supports The available evidence suggests that judgements by Agency staff about what constitutes a 'reasonable and necessary support' required by people with disabilities associated with mental illness vary markedly between the Hunter and Barwon trial sites. In NSW, average committed supports for 25 – 64 year olds with primary mental health disabilities was around $33,000 compared to $20,000 in Victoria. Assessments of reasonable and necessary supports appear to vary markedly based on geographical location. In addition, significantly differing patterns of types of support committed have been found in NSW and Victoria. In NSW, a large amount of funding has been committed to supports for daily tasks / shared living and assistance with personal activities. In Victoria, a larger amount of funding has been committed to support for life skills, development and assistance with a life stage transition.	That the Agency build the knowledge, evidence base, organisational practice and tools through its support and development of a specialist mental health/ psychosocial disability team as mentioned above. Monitoring the patterns of resource allocation between States/ trial sites and encouraging stronger peer review by Agency staff across States. Stricter use of better defined reference packages in the allocations of resources for support plans That the Agency explore the development of a validated Australian instrument for determining the severity and permanence of functional impairments and support needs for the NDIS target population.
Predicting future demand from people with disabilities related to mental illness and **influencing future demand** Young People: Future demand for NDIS funded supports from people with disabilities related to mental illness will be significantly impacted by the supply and effectiveness	That the Agency's Scheme design staff, should develop a tool for the NDIA to track the level of services provided for this group by national programs such as Headspace and public and private youth and child mental health

ISSUE	PROPOSED RESPONSES
of clinical services to young people presenting with mental health issues. International evidence indicates that early intervention for young people with emerging patterns of psychotic behaviours can prevent or minimise long term functional impairments and disabilities.	services. If services for young people with presenting psychotic symptoms are not adequate, the Agency should have an advocacy strategy to influence the Commonwealth, State and Territory governments for improved youth mental health services. Such advocacy could be an effective and low-cost early intervention strategy for the Agency.
Funding of mental-health specific support items The NDIA support clusters and funded items provide the current basis for the funding of service packages. These clusters and items offer a broad range of support and equipment items for inclusion in support packages and the current list are appropriate for participants with disabilities associated with mental illness. However, there are several mental-health- specific support items that should be considered for approval on the support items list. These are funding for peer workers, life coaches and advanced independent living practitioners.	Additional support items for peer workers, life coaches and advanced independent living practitioners should be created for participants with disabilities associated with mental illness. That this issue be addressed by the Working Group already set by the Special Adviser, Eddie Bartnik.
Building participant capacity Many participants with disabilities related to mental illness, are able and should be expected to work towards building their skills and capacities in social and future economic participation. Support planning should focus on building skills and capacity amongst participants, consistent with insurance principles, even if they are not requesting such assistance to maximise their independence, employability and contribute to the financial sustainability of the Scheme. This ability to build skills and capabilities needs to be recognised and encouraged in participants' individual plans.	The recommended specialist mental health/ psychosocial disability team within NDIA Head Office should be given responsibility for building capacity development for participants with disabilities related to mental illness into operating guidelines and staff training for support planning staff.

Impacts of funding and policy shifts in the mental health sector

The Council wishes to advise the Board of a significant policy and funding issue that is likely to become a major challenge and risk that will need to be carefully managed by the Agency next year (2015). The funding design for NDIA originally committed transition of funds from a range of Commonwealth-funded community mental health services. They include Personal Helpers and Mentors (PHaMs), Partners in Recovery (PIR) and a range of other programs; some targeted at families and carers of people with mental health issues. It is difficult for the Council to identify exactly the level of funding involved, but our understanding is that it is in the order of $800 million in forward estimates. Funding for these programs is scheduled to cease over the next 12 months with a significant number of contracts ending on June 30, 2015 unless there are further contract extensions. Many participants, staff and agencies will be affected. This is likely to become a public issue in the first half of 2015.

While this is an issue for Minister Fifield and the Department of Social Services to manage, we forecast that the Agency will be drawn into the debate for several reasons. First, some State and Territory Governments are assuming that (and advising consumers and agencies that) the NDIS will or should be inclusive of this group of participants who are currently receiving services. While this will generally be correct for users of the Partners in Recovery Program, current users of PHaMs and family mental health support services are unlikely to be eligible under the severe and persistent criteria in the NDIS guidelines. Significant numbers are likely to have access to these services withdrawn.

Second, the community mental health sector and some State and Territory Governments are concerned about the impacts of this change and the impacts on people who are currently receiving supports under these Schemes who will miss out. This may be an unintended consequence of the process of putting together the funding package for NDIS. Some in the sector consider that this funding problem requires the Agency to be flexible in responding to episodic functional impairments due to a mental health issue. This matter, will in our opinion, place pressure on the Agency in regards to its interpretation of severe and persistent impairments associated with mental illness. This report has identified a lack of national consistency and the need for the Agency to strengthen its eligibility criteria and practices in the determination of severe and persistent disabilities associated with mental illness. The IAC consider that this issue may emerge as a significant issue in 2015 that the Board needs to be aware of and carefully manage. It has the capacity to do reputational damage to the Agency if this does not happen. We understand that our Chief Executive, David Bowen has recommended that the Department extend the contracts for PHaMs and family mental health services, which would be a sensible resolution to this issue. The problem is compounded by states such as Victoria who are shifting all their current funding for mental health community support services into their contribution to the NDIA and leaving no recurrent funding to meet their obligations under the COAG 2012 agreement to deliver recovery and rehabilitation services to people with mental health issues. The community mental health sector is rightly arguing that funding arrangements for NDIS are resulting in a significant reduction in community mental health services. Our advice is that this is a Commonwealth, State and Territory policy and funding issue, yet the Agency may be drawn into this it.

The Independent Advisory Council considers that the adoption of a “Mental Health Implementation Plan” that includes the elements recommended in this report, would allow the Agency to build its responsiveness to the specific needs of this participant group, build its technical capacities in eligibility assessment and planning support and manage participant and community expectations of the Scheme for people with disabilities associated with a mental illness.

We commend this report to the Board.

1. Introduction

The inclusion of people with disabilities due to mental illness into the National Disability Insurance Scheme is a significant step forward in social policy and heralds much needed support for a population group whose needs have been inadequately met in the past. This group was projected to constitute between 10% and 15% of the participants in the Scheme and is therefore are significant sub-population of the Scheme. The inclusion of people with disabilities arising from mental health issues into NDIS occurred after the initial scheme design and had strong support amongst all State and Territory governments and community groups during the NDIS Consultations in 2012. This report starts from the principle that the Federal Parliament and State and Territory Governments have defined the frameworks and the principles for the treatment of people with disabilities associated with mental illness (PDMI). It starts from the premise that there are some distinct needs and requirements of this group and that the task of the NDIA is to make the Scheme work as effectively and efficiently as possible for this participant sub-group. The purpose of the trial period of the Scheme is to learn, adapt and develop and this report is a significant contribution to this important phase of the Scheme.

The IAC has identified the need to give consideration to improving the responsiveness of the Scheme to people with disabilities related to mental illness. As part of its work plan, it commissioned two of its members with expertise on mental health and psychosocial disability related to mental health issues, Gerry Naughtin and Janet Meagher AM, to prepare a paper on the key issues for the Agency to consider in implementing NDIS for people with disabilities related to mental health issues. This work was undertaken through conversations and discussions with fellow Council members, critical reflections on presentations and discussions with staff from the Agency, selected experts and people in the mental health sector, and Mr Eddie Bartnik, the Strategic Advisor to the NDIA on mental health and psychosocial disability and Ms Sarah Johnson, the Scheme Actuary.

As part of this report's development, a literature review was commissioned by Mind Australia and the IAC and undertaken by the Centre for Mental Health, School of Population Health, and University of Melbourne with input from Mind staff.

The literature review addresses eight key topics:

1. The concept of 'permanent' impairment and its usage elsewhere, including existing rules set by other schemes and their application in practice in determining appropriate supports and whether impairment is considered permanent.
2. The likelihood of 'permanence' of certain forms of mental illness and the possibility of predicting the long-term course of a particular disorder for a particular individual.
3. The concept of 'reasonable and necessary' supports for people with psychosocial disability and how this is used and applied elsewhere.

4. The impact of psychosocial disability arising from mental illness on individuals and the evidence for the nature and extent of psychosocial impairment and its implications in terms of functional impairment.
5. Preferences for support of people with a psychosocial disability arising from mental illness, in relation to the categories of activity in which an individual may experience impaired psychosocial functioning.
6. Common supports used by people with a psychosocial disability arising from mental illness.
7. Gaps between the support preferences of people with a psychosocial disability arising from mental illness and existing services in Australia.
8. The evidence for the effectiveness of different supports, and limitations of that evidence in relation to people's preferences.

The reviewers set out to consider the evidence on the nature of the disabilities that occur because of severe and persistent mental health issues. The literature review has helped form some of the judgements and perspectives presented in this report and will be made available as a separate resource for the Council, Board, Agency, and the mental health and disability sectors.

In this report we consider the issues and propose a set of actions to assist the NDIA/NDIS to be more informed and responsive to the specific requirements of the participant group in question. The IAC recognises the scale of change that the NDIS represents for people with mental health issues and mental health and primary care services. Notions of individualised funding, choice and control are new to many people with significant mental health issues, who have often had none or very limited choice let alone control in their history of seeking support with their mental illness or support needs. The state of readiness of this population group for NDIS is lower than in the community of people with physical, intellectual and sensory disabilities. There are some specific barriers to access for this population group that need to be addressed.

This report is structured around the issues that the IAC has identified in its analysis. Each of these themes has a brief description, followed by a discussion and suggestions of possible ways forward to address the issue for consideration by the NDIA Board. The IAC acknowledges that some of these recommendations may require further discussion and sector engagement in their implementation.

The IAC acknowledges that it is still early days in the Scheme and that the available data is still preliminary. Some of the judgements formed in this report will need to be refined and developed based on the data and feedback that will become available over the next few years.

This report provides advice to the Board of the National Disability Insurance Agency on strategies for improving the responsiveness of the NDIS to people with disabilities related to severe and persistent psychiatric conditions.

The final point that needs to be understood as part of the context for this paper is the use of the terms related to mental illness. The NDIS Act defines eligibility on the basis of one or more impairments attributable to a psychiatric condition that results in substantially reduced functional capacity in relation to communication, social interaction, learning, mobility, self-care and self-management. This language has been unfamiliar to many consumers and practitioners and resulted in some confusion about entitlement in the broader community from the outset. Current language used by many consumers and their families and carers, as well as service providers, includes terms such as "mental health", "mental health issues", "mental illness" "recovery", "rehabilitation" and "mental ill-health". Developing a shared understanding of the terms used and a shared language will become more important over time. One example is that the NDIS Act relates "disability" to "impairment in relation to psychosocial functioning". For many people the term "psychosocial disability" is the preferred term as much time has been spent on developing a clear definition. For the purposes of this paper "psychosocial functioning" equates to "psychosocial disability" which is defined as:

> *"Psychosocial disability is a term ...... to describe the disability experience of people with impairments and participation restrictions related to mental health conditions. These impairments and participation restrictions include loss of or reduced abilities to function, think clearly, experience full physical health and manage the social and emotional aspects of their lives."*
>
> *A psychosocial disability is one that arises from a chronic "mental health issue that affects people's daily activities such as socialising or interacting with others in a social setting, learning or self-care, or their capacity to fully participate in society[i]" and is present over an extended period of their life span.[ii]"*

In this report we have tried to use the same terms that are used in the NDIS Act but at times, and in particular in relation to discussions about the sector and Tier 2 services, the preferred language of the sector is used due to its more inclusive scope. The intent is that the terms are considered to be interchangeable throughout this report.

The authors wish to acknowledge the assistance, support and advice of Agency staff during the preparation of this report. In particular, we wish to thank Ms Liz Cairns, Chief Operating Officer, Mr Eddie Bartnik, Special Adviser to the NDIA, Ms Sarah Johnson, Scheme Actuary and Ms Alex Madsen from the NDIA Governance Section. We also acknowledge the significant contribution of Mr Ben Kite, a senior policy adviser working with Mind Australia on the preparation of this paper.

2. Key Issues

This section considers twelve design and operational issues that need to be addressed and monitored in implementing the NDIS for people with disabilities related to a psychiatric condition. These are:

- Interpreting permanency
- Assessing of the degree of impairment
- Defining reasonable and necessary supports
- Responding to participants' fluctuating needs
- Developing, supporting and utilising individual support plans
- Preventing demand – monitoring of youth and child and adolescent mental health services
- Building participant capacity
- Less informal support
- State and Territory Governments' role in the provision of community rehabilitation and recovery-oriented services
- Development of Tier 2 services – to address dependence issues
- Requirement for information and knowledge
- Funding of mental health specific support items
- Sector engagement

For each of these issues, the paper outlines a brief description of the issue, followed with a discussion and suggestions of possible ways forward.

2.1 Interpreting permanency

What is the issue:

It is apparent that consistent determinations of 'permanency' of disability are hard to arrive at under the current assessment processes. One of the objectives of the NDIS Act is to ensure the provision of a nationally consistent approach to access, planning and funding of supports. Our observation is that there are significant variations across the pilot sites in the assessment of eligibility. This lack of consistency is compounded by definitional ambiguities in the NDIS. Anecdotal reports and preliminary data indicate a higher rate of ineligibility rulings on access requests from people with psychiatric conditions compared with other participant groups. One in four applications based on a disability associated with a psychiatric condition are being ruled ineligible by the Scheme as compared with one in nine across the Scheme. In addition, there are a significant number of access requests lodged in the system have not been followed through by applicants. The reasons for this variation require further examination and need to be considered in the broader context of interpreting the criteria of severe, persistent and episodic functional impairments for this population group.

Discussion:

The requirement of the NDIS Act that impairments be permanent or likely to be permanent in order for a person to be eligible for the scheme creates particular challenges in relation to disablement arising from psychiatric condition. The difficulty is that the NDIS Act provides no definition or clarification of the concept of permanence to assist in implementation and there are not Australian or internationally accepted benchmarks upon which to base determination of the permanence criteria[iii]. To be eligible for the NDIS the disability impairment needs to be permanent, yet the Act does not define permanence and recognises the episodic nature of mental illness. This situation may result in unintended and inconsistent access to NDIS. The Agency needs to move towards its own working definition of permanency.

For people with an impairment related to a psychiatric condition the definition of permanence is made more difficult by the episodic nature of psychiatric condition[iv]. The NDIS Act and the operating guidelines recognise the episodic nature of mental health issues. This is positive for participants but makes the assessment task more difficult. The complexity of the definitional task for this population is also being recognised in other areas of social policy. The McClure Report proposes a firmer distinction between ‘permanent’ and ‘episodic’ disability for the purposes of access to the Disability Support Pension (DSP) but does not offer any guidance about how this might be achieved. Developments emerging from this report will need to be closely monitored given the potential interaction between the DSP and NDIS. In addition it needs to be appreciated that for people with mental health issues, functional impairments can be cumulative and on-going even when the symptoms of the psychiatric condition are not on-going or permanent. That is, the disability can continue even when the symptoms of the condition are not active or present. Greater weight must be given to functional impairment than diagnosis in the determination of disability permanence.

The National Disability Insurance Scheme has been designed around the principle of entitlement to support. Such entitlement will ensure that those Australians with a disability who meet the criteria for inclusion in the Scheme receive the supports they need so they can participate in the social and economic life of our community. This is a significant shift in emphasis from the previous arrangements which were predicated on the basis of provision of disability supports through a budgeted amount of funding unrelated to demand.

The principle of entitlement is fundamental to the Scheme’s success. This principle of entitlement needs to be retained in the current debates on the size of the Tier 2 and Tier 3 population groups and in debates about language, terms and possible meanings. The experience of insurance schemes elsewhere suggests that effectiveness may be subject to escalating costs as more people draw on the scheme and/or it is required to fund greater levels of support. In some circumstances, tightening eligibility then becomes a mechanism for managing costs.

It is important to note that not all mental health consumers will develop a psychosocial disability and require support to participate in the community even if they have a diagnosis of a major mental illness. Despite their diagnosis many will achieve a quality of life that enables their social inclusion. Some people require supports intensively and continuously and others will require supports only episodically[v]. Even amongst those who have severe and persistent mental health issues, there will be a number whose experiences leave them with mild impairments but remaining capable rather than disabled by their experiences. For this reason psychosocial disability can be a vastly differing experience, with diverse impacts, degrees of severity and varying outcomes even from within the same diagnostic groups and will fluctuate in its intensity over time[vi]. The only valid process will assess functional impacts.

The practical challenge will be in making reliable assessments of the permanence and significance of a person’s impairment. The current process for the determination of permanent or lifelong disabilities draws from a range of sources of information in making a determination. These include the expressed needs and preferences and information provided by the applicant, clinical assessments of diagnosis and judgements about functional impairment, historical service usage data, information from family members and service providers. A standardised assessment process and tool (SNAT) is used by the Agency to collate available sources of information and professional judgements in their determination of permanence. This tool is not a tested or validated instrument and there is an inevitable level of subjectivity and variability to the judgements made by Agency staff and the external clinical and functional judgements upon which they rely. As the literature review has shown, there is no direct correlation between disease diagnosis and the level and permanence of functional impairments. The Agency guidelines put considerable weight on diagnosis of psychiatric condition in the determination of eligibility. Our report suggests that stronger weight needs to be given to the permanence and variations in functional impairments, to social factors and individual variability in dealing with functional limitations in the determination of eligibility.

Use of this type of assessment is also highly dependent on the skills of the assessor and in the case of people with a disability related to a psychiatric condition the assessors’ knowledge of disability and of psychiatric conditions. As the method is subjective the assessors require exposure to and a strong knowledge of psychiatric conditions.

Such a person-centred approach to assessment of permanency and hence eligibility is a reasonable response that reflects a number of aspects of good assessment practice. However, the outcomes of this approach need to be carefully monitored over the next 2 years to assess the consistency of approach across the trial sites, the way in which assessments are responsive to episodic presentations of mental illness and how accurate the external assessments of permanence are. The judgements about permanency and hence eligibility for people with a disability related to mental health issues will be subject to appeal at the Administrative Appeals Tribunal. The Agency needs to have an evidence based rationale for its approach to the assessment of eligibility for this participant group to respond to such appeals.

Practice in relation to definition of severe and permanent and episodic have been developed and refined in each of the trial sites. Our observations, confirmed by some Agency staff is that the definitional issues are complex and Agency staff make their best endeavours to interpret the available assessment reports. Some staff undertaking such assessment either do not have experience in working with mental health clients and interpreting technical assessment data or have a purely clinical diagnostic approach. The Agency approaches rely heavily on external clinical reports/assessments of the disease rather than permanency of the disability for people with mental health issues. The difficulty with a reliance on such assessments is that many of these reports are based on an assessment of diagnostic characteristics rather than functional impairments.

The literature review undertaken as part of this report identified this as an issue experienced by a range of insurance schemes with no simple or obvious solutions. The matter has been addressed in a number of ways including: clinical assessment requirements; duration of disability requirements; the degree of functional impairment caused by the disability and; the likelihood that the disability and functional impairment would continue into the future, which may be based on predictors of illness course and outcomes. This is a complex technical issue and an area of vulnerability for the Agency unless it develops its own working definitions and criteria of permanency of disability and development of tools to support people with mental health issues for use by both its own staff and staff in external agencies making judgements about the assessments upon which it relies.

Recommendations:

There is a need to work purposefully to address these issues. This work also requires the development of preferred changes in operational guidelines and language as well as the implementation of such changes over the next 2 years. The scheme needs to transition to a more nationally consistent approach and such consistency will require clearer guidelines in the interpretation of severe and permanent and take into account variations in intensity and support over the participant's lifetime. The Agency needs to build its technical capacity on this issue. The IAC recommends the following strategies to address this issue:

- The creation of a specialist mental health/ psychosocial disability team at the NDIS Head Office with expertise in assessment of eligibility, reasonable and necessary supports and support planning and review for people with disabilities related to mental illness as well as mental illness and other disabilities, in particular intellectual disability and autism.

- The development by the Agency of its own evidence-based working definition guidelines and tools to determine severity and, permanency and respond to the episodic nature of disabilities related to mental health issues.
- The promotion by the Agency of its working definition of permanence of disability related to mental health issues within the Agency and an undertaking to provide training on the determination of permanency to assessment and support planning staff.
- Publicise these working definitions and operational guidelines to staff and agencies in the mental health and primary health care sectors.

2.2 Assessment of the degree of functional impairment

What is the issue:

To be eligible for the NDIS, in particular, Tier 3, the disability impairment related to a psychiatric condition needs to result in substantially reduced functional capacity, in one or more of six areas. The determination of reduced functional capacity is a complex matter and there are no widely adopted guidelines to help frame consistency. Assessment reports are often based on diagnostic evaluations and criteria and not on functional assessments. The Agency has no validated and hence consistent way to determine substantially reduced functional capacity for people with a disability impairment related to a psychiatric condition which has potential to result in inequitable access to NDIS.

Discussion:

The literature review found that severe mental illness more often than not results in some level of disability and that functional impairment can occur in most facets of daily life including the ability to work or study, socialise and take care of a home. It found that social and occupational functioning seem to be particularly impaired and as a result, people with severe mental illness are often unemployed, single and socially isolated. The level of disability varies between people with a mental illness, but also within the individual with a mental illness over time, depending, in part, on fluctuations in the severity of symptoms at any particular time and the types of symptoms experienced. The findings from the literature suggest that resultant psychosocial disability can be persistent and enduring, lasting for decades. While functional impairment can decrease if symptoms remit, people with a mental illness most often continue to experience some level of functional impairment in a variety of areas, even if their symptoms are no longer seen at a ‘clinical’ level. One of the primary reasons that people with a mental illness experience an impaired ability to function in aspects of their everyday lives, even when symptoms of the mental illness have improved, is because they experience cognitive impairment, such as difficulties in processing and remembering information.

The disability requirements of the Act largely focus on functioning and participation. This approach is consistent with that of the World Health Organisation (WHO) International Classification of Functioning, Disability and Health (ICF). However, it does not offer an adequate tool for the assessment of functional impairments common with most mental health issues. The WHODAS v2 has come out of the WHO work on the international classification of functioning and does offer a practical instrument for the assessment of the level of difficulty for this group but does not point to the level or type of support assistance required. Reliable instruments exist in some disability areas (such as the Care and Needs Scale for ABI) to provide professionals with clear guidelines for the determination of impairments and support requirements. However, there are currently no commonly accepted and used instruments for assessing functional impairments and indicating support needs related to disability due to a psychiatric condition. The provision of such an instrument would provide the NDIA and the mental health sector with clearer guidance and a validated tool for the assessment of functional impairment. Such an instrument may also contribute to the financial sustainability of the Scheme. Some of the leading world experts on ICS and WHODAS are based in Australia and have the knowledge and capacity to develop an appropriate instrument.

In the absence of an instrument for accurately assessing functional impairment and support needs associated with a psychiatric condition, careful consideration needs to be given to the range of evidence available to determine functional capacity. Until a robust instrument can be developed, or adapted from existing instruments, careful and regular review is needed of the variety of ways in which eligibility and support needs are being determined and how consistency of approach is being achieved across the trial sites. Such an instrument could reduce review costs and provide more consistent assessments.

Recommendations:

- As per 2.1.
- That the Agency explores the development of a validated Australian instrument based on ICF/WHODAS for determining severity of functional impairments and support needs for the NDIS target population.

2.3 Defining reasonable and necessary supports

What is the issue:

The observations and discussion about assessments suggest that judgements by Agency staff about the reasonable and necessary supports required by people with disabilities associated with mental illness vary markedly between the Hunter and Barwon trial sites. In NSW, average committed supports for 25 – 64 year olds with primary mental health disabilities was around $33,000 compared to $20,000 in Victoria. Assessments of need appear to vary markedly based on geographical location.

In addition, significantly different patterns of types of support committed have been found in NSW and Victoria. In NSW, a large amount of supports have been committed for daily tasks / shared living and assistance with personal activities. In the Victorian site, however a larger amount of support has been committed for life skills, development and assistance with a life stage transition.

The reasons for this are complex and needs to be further understood. We have observed that NSW and Victoria have had different approaches to community mental health support and this may be reflected in the assumptions and judgements of assessment and support planning staff. Each of the trial sites has been developed in response to the requirements of the pilot region and inter-sites comparisons are only commencing. These variations in the patterns of assessment of what constitutes reasonable and necessary supports is quite stark and suggests that the interpretation of operational guidelines by staff within the trial sites is also impacted by professional cultural influences and individual staff assessments of what might be reasonable and necessary. The financial and operational challenge over the next few years is to achieve stronger national consistency and a more consistent application of an evidence base to resource allocation judgements. Such practice development is essential if the “entitlement charter” of the Scheme is to be consistently applied for people with disabilities associated with mental illness.

An evidence base for the determination of “reasonable and necessary supports” will prove to be an important tool for fair and equitable resource allocation of a disability support scheme of the scale of the NDIS. However, there are no empirical markers of what are ‘reasonable and necessary’. The leading study on such markers in mental health, the National Mental Health Planning Framework has not been released publicly. The challenge is to develop some more objective markers of reasonable and necessary supports for people with disabilities related to a psychiatric condition and use these to ensure a more nationally consistent and cost-effective approach to NDIA allocation practices and to help frame participant expectations will be available based on groups of needs.

Discussion:

Decisions about what constitutes reasonable and necessary supports are central to the operation and financial sustainability of the Scheme. While there is considerable research on the supports used and required by people with disabilities related to psychiatric conditions in Australia[vii] there are no empirical markers of what are reasonable and necessary supports for people with disabilities related to psychiatric conditions. The NDIS Act 2013 identifies the following criteria of what is reasonable and necessary: support to pursue goals and aspirations, social and economic participation, value for money, likely to be effective and beneficial for the participant, incorporates reasonable expectations of families and carers, supports appropriately funded through NDIS and supports that should not be funded because they should be funded through other service systems. These criteria are aspirational, provide a broad basis of what is reasonable and necessary and individual elements may conflict with other elements. Assessors need to balance up each of these elements and the wishes and preferences of the participant in forming an opinion about what is reasonable and necessary.

For people with a psychiatric condition the level of functional impairment varies between individuals and also within an individual over time. Individual functioning will change due to the episodic nature of psychiatric conditions, severity of symptoms and the types of symptoms experienced. One of the primary reasons that people with a psychiatric condition experience an impaired ability to function in aspects of their everyday lives, even when symptoms of the psychiatric condition have improved, is that they can experience cognitive impairment, such as difficulties in processing and remembering information. There is also a range of symptoms and conditions that may complicate the assessment of functional impairment and the subsequent support requirements. These include conditions such as anosognosia (the vehement denial of the presence of psychiatric issues), demotivation and social presentations that are sometimes dysfunctional, bizarre or distressing and complicate the determination of need. In addition many participants with a disability related to a psychiatric condition will not have family members, carers, informal networks or community members who can reasonably be expected to assist in the provision of informal support.

Funding and provision of NDIS support needs to take account of what it is reasonable to expect families, carers, informal networks and the community to provide. Yet the nature of severe and persistent psychiatric conditions can create a heavy strain on relationships between people with mental health issues and their families and carers and other informal supports. Emotional burnout is common, and people who have had severe and persistent psychiatric conditions over a long period of time may lose contact with their families entirely, becoming highly isolated. People with similar ‘starting points’ can experience very different outcomes over a period of time because of differing levels of informal support.

This means that many participants with a disability related to a psychiatric condition will not have family members, carers, informal networks or community members who can reasonably be expected to assist in the provision of informal support. This group commonly experience social isolation with a large percentage living alone, having few or no friends, and experiencing high levels of unemployment[viii]. The implication of this reality is that NDIS planners may not be able to expect the same level of informal support from families and carers than may be reasonable in other population groups. This factor needs to be recognised and factored into the funding of individual support plans and the assumptions underlying reference packages.

The literature review identified that relatively few Australian and international public insurance schemes use the terms ‘reasonable‘ and ‘necessary’ support or any similar concepts in determining appropriate support services for intended beneficiaries. Where the terms ‘reasonable and necessary’ are used they tend to refer to the use of evidence-based treatments and supports with demonstrated efficacy in promoting recovery or rehabilitation for a particular disorder, the cost-effectiveness of that intervention, and the delivery of the intervention by an appropriate practitioner for only the duration that the intervention has an ongoing benefit. The needs of the individual and resulting payment of benefits are often determined using an assessment of the disorder and resulting impairment, and of the individual’s personal needs. Such assessment focuses on the type and severity of the disorder(s) experienced, the complexity of the impairment and individual characteristics of the person such as their aspirations, goals and needs. In determining the level of benefit to be received to provide reasonable and necessary supports, a variety of approaches are used, including clustering of disorders that attract a particular level of payment, placing upper limits on payments made for particular types of services, and use of available historical service use patterns.

Support requirements are influenced by a range of factors including personal, structural and social circumstances. For people with a disability related to psychiatric conditions functional impairment can occur in most facets of daily life including the ability to work or study, socialise and take care of a home. There is a level of complexity of assessing functional impairment and the corresponding reasonable and necessary supports in activities such as social interaction and self-management for people with a disability related to psychiatric conditions.

NDIS is using reference packages to cluster support needs, expenditure and clusters of services required. This has been done because of the lack of validated and acceptable instruments, the focus on choice and control in the legislation and the need to build an adequate Australian data base to demonstrate a picture of what is reasonable and necessary. There is a diverse suite of issues in the interpretation of what is reasonable and necessary from a participant, family, Agency staff and service provider perspectives. For example, is it reasonable and necessary to provide taxi services for transportation rather than the costs of public transport usage? There is a trade-off between choice, cost and efficacy in the determination of reasonable and necessary.

The approach adopted by the Agency is consistent with the Act and the use of reference packages is a sensible and practical method for building a picture of assessed and preferred judgements of reasonable and necessary. The approach moving forward in the determination of reasonable and necessary for people with disabilities related to psychiatric conditions should build on a person centred approach and respond to individual needs and circumstances while recognising and adjusting for standardisation of need over time. The development and continued use of reference packages should be encouraged and consideration should be given to publishing the outcomes of reference packages, when more reliable package data is available. The ICF and its domains provide a solid framework for defining the elements of reasonable and necessary. It is reasonable for the Agency to start to define what it considers is reasonable and necessary on need and cost grounds and to acknowledge that choice and control has limits. It is also reasonable for the Agency to publicise its guidelines about what is reasonable and necessary and such guidance can be helpful for participants and their advocates and Agency staff.

Recommendations:

- As per 2.1 and 2.2.

2.4 Funding of mental-health specific support items

What is the issue:

The NDIA support clusters and funded items provide the current basis for the funding of service packages. These clusters and items offer a broad range of support and equipment items for inclusion in support packages and the current list are appropriate for participants with disabilities associated with mental illness. However, the IAC considers that there are several mental-health specific support items that should be considered for approval on the support items list. These are funding for peer workers, life coaches and advanced independent living practitioners.

Discussion:

In Australia, there is strong experience and evidence base for the effectiveness of three specific support roles that are not specifically covered in the NDIA support items list - peer workers, life coaches and advanced independent living practitioners.

The use of a key worker or support worker with a minimum Certificate IV in Mental Health qualifications and the skills to effectively engage and work with participants has been proven to be a successful approach to effective support. This approach has been based upon a key worker who has a competency set that reflects the ability to assist with meeting a broad range of individual support goals; work with individuals who have a high level of complexity; and work effectively and safely in the context of psychiatric conditions. The nature of the product or service stream that has been developed in mental health is different to attendant care and to professional services. The minimum qualification that is regulated by State and Territory Governments is generally Certificate IV and higher level qualifications. While there may be scope to include some of the functions of life coaches and advanced living practitioners into existing support clusters, the IAC considers that a review of the current clusters and individualised support items for participants with psychiatric conditions should be undertaken and consideration given to the addition of support items for peer workers, life coaches and advanced independent living practitioners.

Recommendations:

- That additional support items for peer workers, life coaches and advanced independent living practitioners be created for participants with disabilities related to mental illness.

2.5 Responding to rapid and significant variations in support needs

What is the issue:

The support needs of participants with a disability related to a psychiatric condition support needs may change quickly due to the rapid, episodic onset of mental illness symptoms. Support plans and review processes need to be designed to be able to respond quickly and flexibly to these changing needs.

Discussion:

For people with a psychiatric condition the level of functional impairment varies within an individual over time. Individual functioning will change due to the episodic nature of psychiatric conditions, severity of symptoms and the types of symptoms experienced. The episodic nature of mental illness symptoms may mean that more intensive supports may be required during a period of significant illness and then be able to be reduced again when the illness symptoms have subsided.

This means that consideration needs to be given to ensuring there is flexibility in the provision of NDIS supports to meet the fluctuating needs of this participant group. There is a range of possible strategies that could be put in place to ensure timely responses to such fluctuating needs. These include:

1. Planning for variations in support plans in advance, with all parts of the service system, when the participant has capacity and insight, could ensure that the Agency and support providers can respond quickly to changing needs and ensure that accountability and approval requirements are in place. Providing support plan staff with the flexibility to vary support levels quickly on a temporary basis based until a formal review is undertaken.
2. Streamlining variation approval processes to ensure they do not impede rapid responses to changing needs.

Recommendations:

- That the Agency reviews Operating Guidelines to ensure that policies and procedures are flexible enough to respond to rapid and significant changes in support needs.

2.6 Developing, supporting and utilising individual support plans

What is the issue?

Feedback is indicating that some applicants with mental illness are finding the process and timelines of the Scheme difficult to engage with. The notions of choice and control are new for many people and while engaging, some participants need more assistance in understanding the opportunities that NDIS can offer in their lives and the processes and stages in support plans.

Tracking and analysing the experience of participants with mental illness in relation to support planning and review would assist improving and refining these processes.

Discussion:

Developing an individual support plan with participants requires the ability to build a trusting working relationship with the NDIS participant that will facilitate an open discussion on goals and aspirations, strengths, abilities and opportunities for development, along with daily support needs. The development of a responsive support plan is an iterative process that is developmental in nature and needs to be able to adapt to fluctuating needs. Cognitive impairments, understanding of the Scheme and motivation to engage are all individual participant factors that can result in longer periods of time and more meetings and contacts in the development of a support plan. Our consultations are indicating that the staff of the Agency are working very constructively to build trust with participants allocating significant time to discussions on goals and how to achieve them. These realities for people with psychiatric conditions also mean that timing for assessment and support planning will take longer than originally scoped in the bi-lateral agreements. Investment of time in building planner-participant relationships, support planning and thorough review will result in better outcomes for the participant and reduced costs for the Scheme. It is important to recognise that the investment in good assessment and support planning is critical to meeting the financial sustainability of the Scheme and that hurrying or truncating these functions may led to a lack of discipline on cost containment.

Our consultations have indicated that in the first 12 months of the Scheme, considerable developmental effort has gone into working closely with mental health and other services to build an understanding of the Scheme and the information requirements of the Agency in determining eligibility and negotiating consent issues. The Scheme is reliant upon good access to diagnostic and support needs information from clinical mental health agencies and rehabilitation and recovery oriented services. All of this work is resulting in the building of a solid base for support planning and comprehensive understandings of short and medium term needs.

A trend that we have noticed is the higher use of support plan coordination particularly in the setting up of support plans for participants with complex needs; some individual support plans may require support coordination to implement the plan. The feedback we have received indicates that Agency staff are using support coordination to negotiate complex and new service arrangements particularly in regard to accommodation. This level of support coordination appears to be higher than originally envisaged for the Scheme.

The experience of the Scheme so far appears to indicate that many people with mental health issues require not only a longer period of time in establishing a meaningful plan and in assistance in the initial stages of plan implementation, but also a longer period of time in fully utilising the resources in the agreed plan. For many participants their NDIS plan is resulting in a significant increase in supports than have been available through NSW and Victorian Government schemes. Understanding the scale of additional support funding available and the flexibility with which such funding can be used are new challenges for participants with disabilities associated with mental illness. This scale of opportunity and the time participants and families and carers may take to understand the new opportunities available may take more time and needs to be understood. This reality ought to be factored into bi-lateral agreements and operational guidelines.

Recommendations:

- Greater use could be made of interim or temporary packages on outcome and logistical grounds.

2.7 Predicting future demand from people with disabilities related to mental illness and influencing future demand

What is the issue:

Future demand for NDIS services from people with disabilities related to mental illness will be significantly impacted by the supply and effectiveness of clinical services to young people with presenting mental health issues. International evidence indicates that early intervention with young people with emerging patterns of psychotic behaviours can prevent or minimise long term functional impairments and disabilities. Hence, an effective tool for the NDIA to track potential future demand is to track the level of services provided for this group by national programs such as Headspace and public and private youth and child mental health services. Stronger investment in such services will reduce demand for NDIA services over the medium and longer and will be a factor in Scheme financial sustainability.

Discussion:

Contemporary practice in mental health services shies away from using labels of permanent diagnosis and disability and focuses on effective clinical interventions and supports to help young people to deal with their mental health. Although the NDIS is formally open to everyone under the age of 65, in practice it will be difficult for young people with a disability related to a psychiatric condition to enter the Scheme because most young people will not receive a diagnosis of permanent disability due to a psychiatric condition until after a period of clinical treatment. In addition, young people will be reluctant to engage with the NDIS because they are unlikely to see their conditions and the impacts as permanent.

Young people with a disability related to a psychiatric condition will therefore largely be supported by mainstream services, particularly clinically based mental health services, during the early years of their condition. Young people's engagement with mental health services is often poor - it was estimated that in 2007 only 31 per cent of young women and 13 per cent of young men with a mental health problem had sought professional help[ix]. Some levels of the disabilities associated with psychiatric conditions in adulthood are preventable if effective mental health interventions with young people are available and accessed.

The NDIS costs and liabilities will be impacted by the strengths, weaknesses and responsiveness of schools, tertiary facilities and youth services as well as clinical mental health services and rehabilitation and recovery oriented services. Service access, service effectiveness, service gaps and funding in the youth and child and adolescent mental health space all have the potential to impact on the future demand and the financial sustainability of the NDIS. Close collaboration between the Agency and clinical youth and child and adolescent mental health services in State and Territory jurisdictions and the effectiveness of youth and child and adolescent programs in mainstream services (e.g. headspace) will be crucial to reducing the level and cost of disability support that these young people may require later in life.

Recommendations:

- That the Scheme Actuary monitors patterns of expenditure and service trends in the provision and effectiveness youth and child and adolescent mental health services in all states and territories in Australia and contrast these with emerging patterns of demand from participants aged 20 years and above with disabilities associated with mental illness.

- That the Board recognises the early intervention opportunity to impact demand on the Scheme from people with mental illness by supporting and encouraging expansion of youth mental health services.

2.8 Building participant capacity

What is the issue:

Many participants with disabilities related to mental illness, are able and should be expected to work towards building their skills and capacities in social and future economic participation. Patterns of functional impairment may be different from those in other participant groups. Support planning needs to focus on building skills and capacity amongst participants, consistent with insurance principles, even if they are not requesting such assistance to maximise participants' independence, employability and contribute to the financial sustainability of the Scheme.

Discussion:

For most people with a disability related to a psychiatric condition, the nature of the disability has some differences from disabilities for intellectual, cognitive, neurological, sensory and physical disabilities. Psychiatric conditions are not necessarily progressive nor are they fixed or definitive in the nature of the permanent impairment and they can vary due to episodic and environmental factors. In addition there is the overlay of stigma which impacts on confidence and motivation which in turn impacts on skills and capabilities. This means that many people with a disability related to a psychiatric condition are able to build skills and capacity in social and economic participation while they are eligible participants of the Scheme.

This ability to build skills and capabilities needs to be recognised and encouraged in participants' individual plans. The building of skills and capacity is important to ensure that the NDIS principles of personal choice and control, independence and self-management and social and economic participation are able to be met. It will also assist with financial sustainability of the Scheme.

At the same time it needs to be recognised that not every participant will want to be building skills in every possible area of their life, at all times. As with all people, sometimes options such as someone doing or helping with the task is appropriate. Skill building is also not necessarily linear. All of this means that enhancing individual capacity needs to be undertaken in a systematic, flexible and effective way. This should include a bias towards access to mainstream services such as TAFE and University and mechanisms for ensuring that learning/skill development activities are achieving their stated goals.

Recommendations:

> That the recommended specialist mental health/psychosocial disability team within NDIA Head Office be given responsibility for building capacity development options for participants with disabilities related to mental illness into operating guidelines and staff training for support planning staff.

2.9 State and Territory Government's role in the provision of community rehabilitation and recovery-oriented services

What is the issue:

The COAG Agreement (7.12.12) resulted in state and territory governments committing to ongoing responsibility for the provision of community based rehabilitation and recovery-oriented services for people with mental health issues. The adequacy of ongoing funding for rehabilitation and recovery-orientated services in the future and effective collaboration between mental health services and NDIS will be important factors in the ability of NDIS to achieve its charter.

Discussion:

The COAG Agreement in 2012 was important in that it defined the ongoing responsibilities of state and territory governments for rehabilitation and recovery oriented services for people with mental health issues. Many people are unaware of this agreement and its implications for state and territory mental health services. There was a perception in some sections of the mental health sector that NDIS would be responsible for recovery orientated services. This perception was reinforced in Victoria by the decision of the Victorian Government to transfer all of its Mental Health Community Support Services funding into its funding commitment towards NDIS. In addition, the previous Federal Minister for Mental Health, Mark Butler had stated that the Commonwealth were planning to transfer current funding for Commonwealth funded programs such as Personal Helpers and Mentors (PHaMs), Day to Day Living in the Community (D2D) and Partners in Recovery (PIR) into the NDIS funding base. While the majority of participants of PIR and Day to Day Living are likely to be eligible for NDIS, a significant number of people using the popular and successful PHaMs program would not be eligible because they would not meet the permanency criteria.

These policy and funding changes have created concerns within the mental health sector for two reasons.

First, there is a concern that state and territory commitment of ongoing funding for people with episodic mental health issues will not be adequate. Compounding this, the loss of the PHaMs, D2D and PIR programs will exacerbate this funding create gaps and lead to service shortfall.

Second, there is a concern that NDIS will not maintain a ‘recovery focus’ in its work. ‘Recovery’ is an approach that has been widely adopted in the mental health sector and is a positive mindset that has a focus on notions of belief and hope in a future where the person will have a contributing life. It includes possibilities of being able to manage with activities of daily living, but also runs much more broadly to encompass a person’s life goals, and resilience in the face of challenges. It is important to note that there are many similarities and synchronicities with the core NDIS principles and the concept of recovery. The language of disability is different from the language of recovery but there are no grounds to suggest that the approach of NDIS will not be recovery oriented. Rather the language of NDIS needs to be more inclusive of a recovery perspective for people with mental health issues. Recovery does not mean cure or cessation of all symptoms. It is about a person discovering their ability to live a meaningful, contributing life despite their symptoms. A person can be ‘in recovery’ even when they experience a permanent impact and functional impairments due to their condition. Recovery is about the individual’s journey, maintaining personal hopes and dreams. Rehabilitation is the process and methods of intervention by service providers and funders to support the management of mental health issues.

Clarity about these distinctions is very important in public discussions about NDIS and mental health.

Perceptions within the mental health sector about NDIS are important to manage and it is essential that the Agency engage with the sector. There are two responses that should be considered:

1. NDIA should be restating and publicizing state and territory governments' ongoing responsibility for rehabilitation and recovery-oriented services and rearticulate the separate and different responsibilities of NDIA and State and Territory Governments.
2. The language of NDIS for people with mental health issues should incorporate a recovery flavour and highlight the consistency between the NDIS principles and a recovery approach to mental health supports.

Recommendations:

- That the Agency restates and publicizes state and territory governments' ongoing commitment and responsibility for provision of mental health related rehabilitation and recovery-oriented services, the importance of collaboration and the agreed separate and different responsibilities of NDIA and State and Territory Governments.
- That the language of NDIS around mental health interests should incorporate a recovery flavour and highlight the consistency between the NDIS principles and the recovery approach to mental health supports.

2.10 Development of Tier 2 services

What is the issue:

The recent focus on the roll out of Tier 2 services is supported and there are some specific requirements of people with mental health issues and their families and carers that need to be taken into account in the design of Tier 2.

Discussion:

Tier 2 services, information and referral to mainstream services are crucial to the architecture of the NDIS and therefore have an important influence on its outcomes. KPMG, in its interim report on full scheme transition, identified Tier 2 as the key to Scheme sustainability "as it is the gateway to effective diversion from specialist supports"[x]. The recent decision of the Board to move toward the development of Tier 2 is welcome.

There are a number of elements of Tier 2 services, accessed by people experiencing mental health issues, which are important to the NDIS. Firstly timely access to Tier 2 services is important in terms of reducing future need for NDIS support. For people who are deemed not eligible for the NDIS (at a particular point in time) and for young people this is important. Secondly, information for people with mental health issues about Tier 2 services needs to be provided in accessible formats and take account of the variation in literacy and numeracy abilities in the targeted population. Use of social media is important as well as the recognition that some people with serious and permanent mental health issues do not have access to the web or have low computer literacy skills.

Our observation is that many people who may be eligible will have a weak understanding of the Scheme and how it may be able to assist them. Consideration should be given to the development of a marketing campaign for potential participants with mental health issues to inform them of eligibility and how the Scheme can assist. The design of such a campaign should factor in the commonalities and differences between this participant group and other disability groups.

Families, carers and informal networks play important roles in the lives of people with mental health issues and section 2.3 highlighted the heavy strain on family and informal relationships created by mental health issues. Information and referral strategies developed in Tier 2 should also target the families and carers of people with mental health issues. They play roles as advisers and supporters to applicants and they need to be included in the targeting of information and referral strategies that are developed in Tier 2.

The effectiveness of Tier 2 services in terms of preventing, reducing or maintaining current levels of service demand will also impact on reducing future need for NDIS supports, contributing significantly to the Scheme’s sustainability.

Recommendations:

- That the specific needs of people with mental issues be taken up by the Agency in its development of a strong and effective Tier 2/mainstream service system to support people who are deemed not eligible for the NDIS, young people, families and carers and the NDIS participants who have non-NDIS funded support needs.

2.11 Requirement for information and knowledge

What is the issue:

The NDIS is a new concept for people with a disability related to a psychiatric condition, their families and carers and the service system. The operation of the Scheme will be enhanced through the provision of information and knowledge.

Discussion:

There are three components to information and knowledge that need to be considered. They are: information on NDIS for participants and their families and carers; psycho-education for participants and their families and carers; and information to service providers who work with people with a psychiatric condition.

Individualised funding and packages have been commonly used for service provision for a number of disability groups for many years. When initially introduced they required a significant shift in participants' thinking from being a more passive recipient of pre-determined services to being an active participant in choosing and purchasing services. For people with a disability related to a psychiatric condition individualised funding and packages are relatively new. The historic block funding of agencies who deliver services to people with a disability related to a psychiatric condition is only just starting to change. People with a disability related to a psychiatric condition, their families and carers have had limited choice in both the provider and the type of support offered.

The NDIS has principles of personal choice and control, independence and self-management. In order for these to be fully realised for the NDIS participants with a disability related to a psychiatric condition the provision of information, awareness, educational programs and pre-planning advice is required. Support with these tasks prior to an access request could be advantageous to the Scheme in preparing this group to exercise enhanced choice and control in the support planning and service purchase phases.[xi].

Other specific disability population groups are being supported to prepare for the NDIS but currently people with a disability related to a psychiatric condition are not receiving any support in this area.

Along with the provision of information as to how the Scheme works, there is also a serious need for education on disability, social responses to disability and positive language and attitudes to disabilities related to mental health issues. This needs to occur at a variety of levels. For example the provision of psycho-education for individuals with mental health issues and their families has come to be viewed as an evidence-based practice for the treatment of schizophrenia[xii]. As a result, family psycho-education is frequently recommended in treatment guidelines such as those of the Royal Australian and New Zealand College of Psychiatrists (RANZCP) for the treatment of schizophrenia[xiii]. Based on recommendations regarding the length and conduct of family psycho-education issued by the Schizophrenia Patient Outcomes Research Team (PORT) [xiv] the RANZCP state that:

"Family psycho-education is a program delivered for at least nine months, in which the person with schizophrenia and family members are helped by clinicians to learn communication and problem-solving skills to solve the many challenges that accompany schizophrenia"[xv].

Such psycho-education for people with a psychiatric condition and their families and carers is effective in building better understandings about mental health and helping to maintain or restore better family relationships and functioning. Given the likelihood of lower levels of informal support for this participant group, trying to maintain and re-establish and rebuild informal supports could improve rates of informal support. Such support could be offered on a group and community basis rather than tied to individual plans.

The third component of information and knowledge is related to Tier 2 services. Given the dependency of the NDIS on Tier 2 services it is important that Tier 2 service providers understand the NDIS, how it works and what it means for participants. Information and knowledge of the NDIS is required by all Tier 2 services that work with people with a psychiatric condition and their families and carers including: specialist clinical services, generic services such as primary care, housing, justice and Centrelink who work with people with a disability related to a psychiatric condition who may not be engaged with specialist mental health services. This will ensure appropriate access to the NDIS plus minimise people falling through the gaps and improve service system efficiency through the clarifying of roles and responsibilities.

Recommendations:

- That people with a disability related to a psychiatric condition and their families and carers are actively supported to prepare and orientate themselves to the NDIS and that DSOs are funded to undertake these functions for mental health consumers and their families and carers.
- That Tier 2 service providers who work with people with a psychiatric condition and their families and carers are actively supported to understand NDIS, how it works and what it means for potential participants.

2.12 Participant populations with specific support requirements

What is the issue:

In consultations and discussions, a range of individuals and organisations have raised the issue of needing to address the particular needs of specific population groups. Responding to the requirements of Aboriginal and Torres Strait Islander participants and their communities has been identified as a priority issue in a number of trial sites and the IAC has a strong focus of the needs of this participant group. The specific needs of other participant groups- people from culturally and linguistically diverse backgrounds and people in the LGBTIQ Communities and, in particular, those exiting juvenile justice or corrections areas whose needs are quite specific, will all require consideration.

Discussion:

In the monitoring and implementation work proposed in this report, specific focus needs to be given to the particular access and support requirements of specific population groups within eligible participants based on their mental health issues. The connection between gender and sexuality identification and long term disability has been established for some time. The particular needs of this participant group are complex and many suffer from marginalisation and exclusion. Program re-design work should test out assumptions about the particular needs of this population group and whether any adjustments need to be made to operating guidelines for this group. A similar approach needs to be taken to engaging participants and potential participants from culturally and linguistically diverse backgrounds that have disabilities related to mental illness. Particular requirements in relation to marketing and engagement with the Scheme and in relation to support plans should be investigated and rolled out in a progressive manner as required.

The more specific issues confronting each of these participation groups require consideration, consultation and operating guidelines development. Work with these participant groups should be undertaken as part of the implementation and monitoring work proposed in this report.

Recommendations:

- That in support planning reviews, consideration is given to the specific individual and community support needs of Aboriginal and Torres Strait Islander participants, people who identify with people from culturally and linguistically diverse backgrounds, LGBTIQ Communities and those exiting juvenile justice or corrections areas.

2.13 Sector engagement

What is the issue:

There has been limited involvement of the mental health sector, including consumers and their families and carers as well as service providers in the design and implementation of the NDIS.

Discussion:

The active involvement of people with a disability related to mental health issues, their families and carers and mental health services providers is important for the success of the Scheme. Regular and appropriately timed consultation and engagement will lead to improvements in the design and operation of the Scheme that will ensure that the Scheme is responsive to the particular requirements of people with disabilities related to mental health issues. Consultation and engagement will also improve the effectiveness of the Scheme in the longer term through improved operating processes in both Tier 3 and Tier 2.

Consultation and engagement needs to be targeted and inclusive, reflecting the awareness and connection of different parts of the sector to the NDIS. Consultation and engagement with the sector needs to become a standard way of working.

Recommendations:

- That the Agency actively engage with all parts of the mental health sector (consumers, their families and carers and service providers) on the continued development and implementation of the NDIS.

3. Conclusion

Some of the elements of the needed responses to people with disabilities related to a psychiatric condition are already in place. Further work is required on the key design, operational and implementation issues identified in this paper, along with the adoption of the possible solutions. This would further strengthen the NDIA strategies on inclusion of people with disabilities related to a psychiatric condition. Some of the matters raised will also prove useful and applicable to a broader range of health related conditions that result in people experiencing disability as a result of the condition.

There is a need to work collaboratively to address these identified issues, continue to identify additional and new issues as they arise, identify changes and modalities that can be trialled during the next 18 months, track actual performance over the few years, and ensure that required changes to operating guidelines are in place before the full Scheme roll-out.

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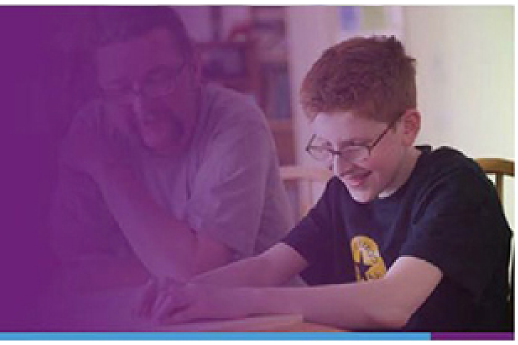

IAC ADVICE TO THE NDIA BOARD: AGENCY RESPONSE

Overview

The National Disability Insurance Scheme (NDIS) Independent Advisory Council (IAC) was established in July 2013 by section 143 of the *NDIS Act 2013*. The role of the IAC is to provide advice to the National Disability Insurance Agency (Agency) Board on how the Agency is delivering the Scheme.

In 2014 the IAC pursued an ambitious work plan and contributed to a range of Agency consultative processes. The IAC's activities culminated in two major pieces of advice:

(1) In December 2014, the IAC provided advice to the Board on how the Agency should approach the provision of 'reasonable and necessary' supports to NDIS participants. This advice consisted of five separate advice papers considering the concept of 'reasonable and necessary' supports in the following contexts:

  - the participant lifespan
  - families
  - planning
  - independence, and
  - self-management

(2) In January 2015, the IAC provided advice on implementing the NDIS for people with disability related to mental illness (psychosocial disability). This advice included the completion of a literature review.

The Board is required to inform the Council of Australian Governments (COAG) Disability Reform Council (the Council) of the advice it receives from the IAC and to advise the Council of the Agency's response. This document represents the Agency's formal response to the Council.

The Agency welcomes the IAC's advice and accepts all of its recommendations. The Agency would like to formally recognise the significant work undertaken by the IAC in developing this advice. The advice will act as a useful reference for full scheme design and will benefit the people at the centre of the NDIS: people with disability, their families and carers. By accepting the IAC's recommendations the Agency is continuing to reinforce its commitment to a culture of continuous improvement.

A summary of the IAC's recommendations and the Agency's response is presented below.

Advice on implementing the NDIS for people with psychosocial disability

The IAC identified improving the Scheme's responsiveness to people with psychosocial disability as a priority. In developing its advice, the IAC focused on opportunities for improving engagement with the mental health sector and mainstream services, understanding existing demand (and predicting and meeting future demand), and consistency in the assessment of severity and permanency in the determination of reasonable and necessary supports.

The IAC emphasised the importance of supporting people with psychosocial disability in their transition to the NDIS. The Agency agrees that this transition requires careful planning, and in this respect strongly supports the IAC's recommendation for the development of a five-year 'NDIS Mental Health Implementation Plan'.

This will be actioned by building upon the existing *NDIA Mental Health Work Plan* (the Plan). The Plan will be progressively broadened to create a five-year plan which will serve as a statement of the Agency's directions and priorities in improving how the NDIS responds to people with psychosocial disability.

As proposed by the IAC, committing to the plan will assist the Agency to appropriately adapt the NDIS for people with psychosocial disability and address associated concerns in a focused and timely manner.

The IAC recommended that the Agency report annually to the Board on progress. Two existing reporting processes will be utilised to report to the Board on the implementation of the Plan: *Annual Report on Scheme Data* and the *NDIA Mental Health Work Plan Report*. This will occur from October 2015.

In reflecting on the IAC's advice, the Agency acknowledges that some of the Scheme's original design elements in relation to access, functional assessments, severity indicators and outcome measures may not have adequately reflected the needs of people with psychosocial disability and current practice in the mental health sector. In response, the Agency is committed to developing evidence-based definitions and guidelines related to mental illness. This is being progressed through the Agency's existing Operational Review of Access for Psychosocial Disability, and also a newly scoped work program to develop reference packages.

The IAC proposed that many of the design and operational issues identified in its advice could be addressed by establishing a specialist mental health/psychosocial disability team at the NDIS National Office. The Agency agrees and is already implementing this recommendation.

The 12 design and operational issues identified by the IAC articulate a clear vision for the five-year plan, and the Agency supports the IAC's proposed strategy for each. The Agency agrees that the following critical issues identified by the IAC should be the focus of the five-year plan:

- developing definitions and guidelines on what constitutes severe and permanent disability related to mental illness
- building a nationally consistent approach to reasonable and necessary supports for psychosocial disability
- predicting and influencing future demand, and responding to variations in support needs
- funding of mental health specific support items, and
- building participant capacity and specific consideration of mental health in the design and implementation of the Information, Linkages and Capacity Building policy (ILC; formerly known as *Tier 2*).

The Mental Health Sector Reference Group will be consulted as a key resource in the development and implementation of all aspects of the Plan. This group was established to develop a robust working partnership between the mental health sector and the Agency. The group held its first meeting in December 2014 and is already contributing to the draft NDIA Mental Health Work Plan. The IAC is has two members on this group.

This renewed approach as prompted by the IAC will ensure the Agency is better placed to support the needs of people with a psychosocial disability.

Advice on the provision of 'reasonable and necessary' supports to achieve an 'ordinary life'

The IAC's advice considered 'reasonable and necessary' supports throughout the participant lifespan. It also applied the concept of 'reasonable and necessary' in the specific context of families, independence, self-management and planning. The advice has been influential in the redesign of the NDIS for full scheme transition.

In considering the concept of 'reasonable and necessary', the IAC developed guidance on how this could be applied to support people with disability to strive for and achieve 'an ordinary life'. The IAC defines an ordinary life as one which includes positive relationships, a sense of belonging, autonomy, active involvement in decision-making, and opportunities for challenge and contribution. This is consistent with a Scheme priority which is to promote economic participation and many of the concepts referred to in the IAC's definition of an ordinary life are achieved through participation in employment, where this is possible. The IAC recommended the concept of an ordinary life underpin decision-making in relation to 'reasonable and necessary' support. The Agency reflects this in its vision which is to optimise social and economic independence and full participation for people with disability.

The IAC advised that the NDIS could better support the realisation of an 'ordinary life' for people with disability. The IAC's recommendations to achieve this and the Agency's response is summarised below.

The planning function

The Agency agrees that planning is crucial to facilitate the opportunities presented by the NDIS. In its advice, the IAC highlighted that currently a great deal is required of the planning process and of planners. The planning function must guide a person through the process of thinking about their goals and aspirations, and operationalise them into strategies ultimately recorded as a statement of supports.

The key finding of the IAC was that the current planning process may not be the best way to maximise participant outcomes. The IAC recommends that the Agency reconsider the planning process in the context of the full participant pathway through the NDIS.

The Agency agrees and is re considering the planning role in the context of Local Area Coordination (LAC) and ILC. A revised planning model which includes the life planning component as described by the IAC, and reconfigures the planning process so that a participant's first experience with the NDIS is not one centred on funding, will be devised for full scheme. The Agency agrees that focusing on the enablers of an 'ordinary life' in planning conversations will provide for better participant outcomes.

A critical component of the IAC's advice focused on participants and their families having the appropriate guidance and support to build a participant's vision for an 'ordinary life' in the planning process. It recommended a number of improvements in this area.

In response, the Agency is already consolidating and improving planning and guidance documents. These changes link the participant led plan and an ordinary life to the context of the participant's life stage. A full review of the key guidance document for planners, the *Cluster and Pricing Guidelines*, will be completed in June 2015.

The exploration and development of an enhanced support co-ordination function as a feature of each plan will also provide the necessary support to continually amend, update and reconsider plans as circumstances change and the participant's confidence in their goals and aspirations increases. The Agency also aims to develop a more flexible approach to the many variations of plan management and financial management in a market driven NDIS.

Capacity building for participants and families

The IAC made a number of recommendations aimed at building the capacity of participants and their families. This included urgent implementation of the Disability Support Organisation (DSO) initiative and the co-design of national capacity building infrastructure.

The DSO initiative is critical to the Agency's capacity building strategy. This initiative is now in place and DSOs are developing their work plans, and over the next two months will incorporate trial site feedback as a first stage of setting up local support groups. The Agency will continue to monitor the development of the DSO network.

The Agency is committed to ensuring participants are supported adequately, with a focus on building individual capacity and skill. Key to this is the development and implementation of ILC strategies and LAC. The ILC policy framework will be consulted on by governments in early 2015. Agency staff have met with the IAC as part of the ILC policy consultation process.

The Agency will continue to implement strategies that promote a participant's capacity to direct their own supports and that promote active involvement by participants in all decisions in relation to their plan. Building capacity to encourage self-management and ensuring it is an accessible option for more participants is an important contributor towards the goals of independence and choice and control. The Agency has already implemented self-management workshops in a number of trial sites, and has begun to include 'support coordination' in participants' plans. The Agency will also hold a co-design workshop to ensure its approach to self-management meets the needs of participants.

The IAC recommended better support and flexibility for families. The Agency agrees that resilient families are a critical factor in ensuring the long-term sustainability of the Scheme. The Agency will continue to develop a more flexible approach to plan development and address the limitations currently experienced through the catalogue of supports. This will be enhanced by emerging natural supports and increased capacity created by the ILC strategies. This work will commence in 2015, as part of a range of strategies to provide flexibility in the choices for participants and their families.

Co-design and inclusiveness for all participants

The Agency is committed to a co-design approach that incorporates the views of participants. It agrees with the IAC that the complexity of issues related to determining reasonable and necessary supports for certain cohorts warrants a specialised body of work. The Agency has recently taken steps to ensure the co-design approach incorporates the views and experiences of all potential participants, including people from rural and remote areas, Aboriginal and Torres Strait Islander and culturally and linguistically diverse (CALD) backgrounds.

A Rural, Remote and Aboriginal and Torres Strait Islander Reference Group has been established to provide overarching, advice and guidance for the development of the Agency's Rural and Remote Strategy and an Agency Strategic Direction for Indigenous people. A CALD Reference Group will also be established in 2015 to provide guidance on the development of the Agency CALD Action Plan. In accordance with the IAC's recommendations, the Agency will consult with the IAC on the work of these groups and the development of relevant strategies.

The Agency recognises the importance of developing a culturally aware workforce and is considering recruitment and retention strategies for people from diverse cultural backgrounds, cultural awareness training and representation of diversity groups in governance arrangements. The Agency will work to ensure that NDIS staff member competencies include the knowledge and skill sets necessary to understand and interact with CALD people with disability in family and community settings and have the attitude to develop relationships based on mutual respect.

Reasonable risk and independence

The IAC recommended the Agency take the lead in adjusting conservative attitudes to risk in service provision, and promote opportunities for reasonable risk-taking. The Agency strongly agrees that participants should have opportunities to exercise an appropriate level of risk in order to participate in the community and further their life aspirations. The Agency recognises that this is directly connected to the goals of the NDIS.

The Agency will continue to provide input into the development of the Quality and Safeguarding Framework, which is being led by the Department of Social Services (DSS). The IAC has already been consulted by DSS on the initial draft framework. The Agency continues to work through the interfacing principles to develop improved practice models to ensure reasonable approaches to participant risk. This will include a strong focus on efforts to reduce the negative impact of existing risk management approaches on choice and control for participants.

The Agency's outcomes framework, when finalised, will address many of the issues raised by the IAC in relation to independence. The outcomes framework considers participant needs over their life span and incorporates changes on a continuum towards independence. The Agency will continue to develop the outcomes framework and will incorporate the key features as outlined in the IAC's guide to independence in major life domains.

The Agency agrees that further work can be done to promote independence and to respect the participant's right to choice and control in the services they receive. This needs to occur through provider learning and capacity building. The Agency is working to promote person centred approaches that respect the right of the individual and promotes practice that has enablement as a key feature. This work will occur in the context of market and sector development, linked to provider registration and ongoing provider capacity building.

In building an appropriate workforce for the NDIS, and in undertaking further work on the efficient price, the Agency will consider how targeted training can be provided to staff that require a specific understanding or skill in order to meet the support needs of a participant. Provider readiness and sector development work will include staff training and capacity building for participants.

The IAC also recommended that the Agency consider innovative ways supports can be provided, particularly in promoting independent and varied living arrangements. The Agency will work in collaboration with all jurisdictions to develop flexible innovative living arrangements for participants. The Agency will continue to monitor the impediments faced by participants relating to accommodation choices. It will liaise with the IAC on further work in this area.

Conclusion

For people with disability, their families and carers, the NDIS represents a lifetime journey which demands an agile and flexible system capable of responding to participant needs across the lifespan. This is the model the Agency is working towards, through the approach of co-design and learning from trial site experience.

The fundamental premise of the NDIS is that people with disability, their families and carers are at heart of the Scheme, exercising choice and control to put in place the structures and supports necessary for them to live the life they envisage. The implementation of the IAC's recommendations will further the Agency's pursuit of these aims.

The Agency will closely monitor the implementation of the IAC's recommendations and will provide progress reports to the IAC and the Board.