Report of the Independent Advisory Council to the National Disability Insurance Scheme

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

October 2014

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Executive Summary

The National Disability Insurance Scheme (NDIS) 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, take 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 how they can assist people with disability to achieve an ordinary life, and
- as an educational tool for the broader Australian community about the role and purpose of the NDIS.

In reading this paper, the reader should be aware that core to the determination of the NDIS is the insurance principles and Scheme sustainability. This means that in providing reasonable and necessary supports, the National Disability Insurance Agency (NDIA) 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 also but 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 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, people of culturally and linguistically diverse backgrounds 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 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 consider ways the concept of an 'ordinary life' could be captured in guidance to planners and participants, while still being consistent with the NDIS Act.

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 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 build 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, a skilled infrastructure is required. Similarly an infrastructure is required if participants want to begin to take on responsibility for staffing or support coordination.

The Council recommends that infrastructure 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 do this 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. <u>Make provision for life planning as part of reasonable and necessary support</u>

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 culturally and linguistically diverse (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. <u>Build the capacity of people with disability and families</u>

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. <u>Local Area Coordination</u>

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. It's 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. <u>Risk enablement</u>

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' is a key concept in the NDIS, being 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' could be used to guide what is reasonable and necessary support. The Council notes that the Agency will need to consider how to reconcile the concept of an ordinary life against the requirements of the NDIS Act.

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 Aboriginal and Torres Strait Islanders, people of culturally and linguistically diverse communities 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 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

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

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 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.

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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., (2012) *Imagining Futures: Identity narratives and the role of work, education, community and family,* Melbourne University Press, Melbourne
[6] Stokes, H., Turnbull, 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
[7] Dept. of Education and Children's Services, South Australia (2007) *South Australian Learner Wellbeing Framework*

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 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)[8] 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[9] confirm this with research that demonstrated that optimal learning occurs 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)[10] 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. Thus 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[11].

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[8] Koen, S & Duigan (2008) "Forging Brighter Futures, paper presented a History and Future of Social Innovation Conference, Adelaide, 19-21 June
[9] 9 Stokes, H., Turnball, M. & Wyn, J. op cit
[10] Rock, P. (1988) Independence: What it means to six disabled people living in the community. *Disability and Society 3(1), PP27-35*
[11] Stokes, H., Turnball, M. & Wyn, J. op cit

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 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 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 the 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)[12]. 56% of the submissions identified exclusion and negative social attitudes as critical issues[13], 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 whilst 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. 27% of the submissions to the *Shut Out* Report indicated that the lack of access to buildings and facilities is a barrier to full participation, while 29% identified 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[14].

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.

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

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[12] National People with Disabilities and Carer Council (2009) *Shut Out*
[13] Op cit. p3
[14] Op cit. p4

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 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 however, 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 an ordinary life. Fear of work health and safety claims have led services to seek 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 his/her family

The attitudes of many people with disability and families are shaped by their negative experiences of being segregated, excluded, marginalized or ignored. This reinforces low expectations and too 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 infrastructure to underpin direct support

Participants who have moved from the NSW self-managed *Community Participation*[15] 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 infrastructure 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 their own staff
- support coordination, or
- professional development of staff.

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.

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

Ensure opportunities for participants to select their own staff

One significant change for these participants is that when staff that have been personally selected leave, the participants are prevented from advertising[16] and so people 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.

Enable participants to purchase training in specific skill sets for staff

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 values and shared interests than to work with staff who don't even share your 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

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[15] Self managed *Community Participation* is a NSW program for school leavers that uses a shared management approach, giving complete control over the what, when and by whom 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.
[16] Service providers argue that unit costs under the NDIS prevent participants from advertising for their own staff

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 go from clients of a capped, crisis oriented state system to citizens supported to purchase reasonable and necessary support to meet their disability support needs.

The planning process must help a person 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 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, critical to reduce participants reliance solely 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 to 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 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.

<u>Building the capacity of people with disability and their families</u>

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.

Families 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 teachers aides often create dependence and get in the way of 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[17]. 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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[17] KPMG, (2014) *Interim Report: Review of the Optimal Approach to transition to the full NDIS*, Joint Standing Committee on the NDIS, (2014) *Progress Report on the Implementation and administration of the NDIS*

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. <u>Risk enablement</u>

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 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.

A small section of this paper would be insulting as a commentary on the additional considerations required to ensure that reasonable and necessary support is framed and provided in ways that enable ATSI people with disability to thrive. A specific piece of work is required.

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 is 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 on the one hand allow greater access due to linguistic and cultural relevance or may impede access due to prevailing stigma or shame around having a person with disability in the family or community. This means that for some, ethno-specific services may be a preferred first point of call 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 so that people of CALD background seem more likely to only seek support at the point of crisis where needs are 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, a small section of the paper would be insulting as a 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 the 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. Flexibility

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 supports to enhance family capacity and resilience.

2. Transport

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.
- 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 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

That 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

Those 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 / self help initiatives.

Recommendation

The Council recommends that the role of the LAC continue to be trialled and refined in the lead up 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[18] 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 55+. The ordinary life analogue highlights the milestones and goals of peers who do not have a disability since both 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.

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

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.

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 rate
	Attending lots of appointments
	Attending early intervention
	Less likely to be at playgroup, childcare
Expectation that specialist supports will	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	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)
	- 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 rate
	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
	- Assistance to make choices (doll or block/)

Issue	Children 2-5
	- Support to take action to get choice
	- 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
	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	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	Tier 3

Issue	Goals	Outcome	Supports	System
	To strengthen integration of child with disability into their everyday family life and the community more generally To minimise concern about the effect of the child with disability on siblings both now and in the future		Encourage and assist to establish use of informal care of grandparents, friends, babysitters	
			Support for inclusion in childcare	Com & 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
	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
			Early intervention	Tier 3
			Encouragement to attend playgroups	All systems
			Childcare	State & Com 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	Families know their rights and advocate effectively for their children	Parent advocacy and capacity building Practical support to assist to participate in capacity building	Tier 2

Issue	Goals	Outcome	Supports	System
	To understand their rights and the rights of their child			
	To understand the interventions needed to support the child To knows what they can do to support their child's development To feel capable in parenting their child	Families help their children develop and learn.	Early intervention Capacity building Practical support to assist to participate in capacity building	Tier 2 capacity building and tier 3 early 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 assist to participate in capacity building	
	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	Tier 3

Issue	Goals	Outcome	Supports	System
			Support to build congruence in everyday family life between needs of child with disability and needs of other family members	
Systemic approaches	Communities have a range of service options and facilities to respond to emerging needs of families in supportive ways Communities value and welcome all members	Early intervention services promote inclusion		Tier 1 information
		Communities are welcoming		LAC/Local Govt. Tier 2
		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 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 rate 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 - Support to 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 - 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 Changed relationships - Experience strong pull of peer group - Form new attachments – dating - Changed relationship with family Increased risk taking
What are children aged 13-15 without disability doing?	Attend secondary school Have friends including dating Play sport 'Hang out' 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 At a loose end 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 - Reframe 'babysitter' support to age appropriate support Strengthen relationships with peers and in community - Strengthen social and relationship skills - Identify strengths and interests as basis for relationships

Issue	Children 13 to 15
	• 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 • 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 his/her skill

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 you enjoy spending 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
	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	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	Tier 3

Issue	Goals	Outcomes	Supports	System
	To strengthen integration of child with disability into their everyday family life and the community more generally To minimise concern about the effect of the child with disability on siblings both now and in the future		Encourage and assist to establish use of informal care of grandparents, friends, babysitters	
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
	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
	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
	To make informed decisions about their child	Families help their children develop and learn.	Information	Tier 2

Issue	Goals	Outcomes	Supports	System
	To feel confident in their parenting		Capacity building	
	To have people to call upon for practical support To have people to call upon for emotional support To have people to call upon to look after their child	Families feel supported.	Support use of informal care of grandparents, friends, babysitters "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	Tier 3
	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
			Professionals and services that assume capacity and work in person centred ways	Tier 2 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

Issue	Goals	Outcomes	Supports	System
		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 • Adapting to physical and emotional changes during puberty Changed relationships • Experience strong pull of peer group • Form new attachments – dating • Become sexually active • Changed relationship with family Thinking about the future • Gain employment • 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
	   o Lack 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
	   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
	   o Lack education and support to build capacity to make decisions related to health
	• Education / training
	   o Struggling to complete secondary school
	   o Struggling to enter and complete post secondary education and training
	• Work
	   o Less likely to have meaningful work experience

Issue	Adolescents and young adults 16-25
	o Less likely to be in inclusive environments - In sheltered employment and day program o Struggling to secure work • Social participation o Less likely to be volunteering o 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 promote challenge	High expectations Work Education Volunteer roles that enhance sense of competence and contribution

Appendix A8: Reasonable and Necessary support for young people 16 to 25 and the families with whom they live

Issue	Goals	Outcomes	Supports	System
R&N 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 - 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 his/her own 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 capacity building
			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 capacity building Tier 3
			Infrastructure to underpin life building support	Tier 3
			Supported decision making in place in all areas of life	Tier 2 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 capacity building Tier 3
			Support in areas of domestic assistance, personal care, travel, communication and finance minimise difficulty	Tier 3
			Skill buildin	Tier 3

Issue	Goals	Outcomes	Supports	System
			All supports assume potential, are person centred and support risk through safeguards.	Tier 3
			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 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
	To plan and establish ones' own 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 one's own home Individual has his/her own home 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 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

Issue	Goals	Outcomes	Supports	System
			Lifestyle support	Tier 3
			Affordable housing	Com Rent 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
			Support to build a vision, a plan, maximise potential and make decisions	Tier 2
			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	Support to build a vision, a plan, maximise potential and make decisions	Tier 2 Tier 3
			Infrastructure to underpin life building support	Tier 3

Issue	Goals	Outcomes	Supports	System
		Individual has a job designed to fit his/her strengths and interests Individual is employed in satisfying work	Thoughtful planning – planning valued social roles, understanding culture of workplace	Tier 3
			Skilled facilitation	Tier 3
			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	State family support
			Behaviour support	Tier 3
			Support for inclusion in local recreational activities	LAC

Issue	Goals	Outcomes	Supports	System
			Support to strengthen extended family and friends in their capacity to engage	
Vulnerabilities	To minimise likelihood of: Low expectations Onset of mental health concerns Will not be included Family unable to continue to care Lack of affordable housing	Individual achieves potential and a positive future Individual moves out of home in a planned basis, preventing out of home care in response to crisis Family has continued capacity to care	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	
			Supported decision making	
				Housing
R&N 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, 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/ LAC
			Succession planning	Tier 3 /tier 2
	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	Tier 2
			Skill building to facilitate connections	
			Information	Tiers 1, 2 and 3

Issue	Goals	Outcomes	Supports	System
	To advocate for services and supports for their family member and their family	Families know their rights and advocate effectively for their family member with disability	Parent advocacy training	Tier 2
			Family advocacy support	Tier 2
	To be able to identify their needs and know how to access available services and supports to meet their needs		Connection to empowering disability networks	Tier 2
	To understand their rights and the rights of their family member with disability			
	To have people to call on for practical assistance	Families feel supported	Flexible individualised support for the person with disability in regular reliable ways and for emergencies	Tier 3
	To have people to call on to care for their family member with disability		Practical assistance with caring roles	
	To have people to call on for emotional support		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 feel confident in their ability to access services and work with professional	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

Issue	Goals	Outcomes	Supports	System
	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		Professionals and services that assume capacity and work in person centred ways	Tier 2 capacity building for services
	To feel confident for the future of their family member with disability with the NDIS To be able to work as much as they want	Families enjoy health and wellbeing	"Whatever it takes' supports to facilitate a healthy well functioning family	Tier 3
			Information, support & vision building	Tier 2
			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 - Reduced control over major decisions in life - Low Self esteem - Lack capacity to grow skills in decision making - Daily living - Little control of daily routines of personal care, shopping paying bills, meals etc. - Relationships and belonging - Isolated, few friends, fewer proportion have partners - Spend time with older people - Not supported to develop intimate relationships - Need for sexual expression often ignored - Home - Younger cohort live with family - Older cohort live in group accommodation - Health - Poorer physical and emotional health than their peers - Key health decisions made by others - Lack education and support to build capacity to make decisions related to health - Lifelong learning - Younger cohort struggling to enter and complete post secondary education and training - Older group disengaged - Work - Less likely to be in inclusive environments - In sheltered employment and day program - Struggling to secure and retain work - Social participation - Less likely to be volunteering - 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
	Support valued roles that promote connection
	Support memberships of interest based groups

Issue	Adults 26-55
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, uncle, aunt
	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
R&N 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 - 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 capacity building Tier 3
			Infrastructure to underpin life building support	Tier 3
			Supported decision making in place in all areas of life	Tier 2 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 capacity building Tier 3
			Support in areas of domestic assistance, personal care, travel, communication and finance minimise difficulty	Tier 3
			Skill building	Tier 3

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

Issue	Goals	Desired Outcome	Supports	System
			Support to develop a practical plan	Tier 3
			Lifestyle support	Tier 3
			Affordable housing	Com 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	Support to build a vision, a plan, maximise potential and make decisions	Tier 2
		Individual is engaged in education / training that is relevant and challenging	Support to make choices in education	Tier 3
			Learning support	Education
		Individual completes of post secondary education and training Individual has skills for work/ volunteering	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 Tier 3
			Infrastructure to underpin life building support	Tier 3
			Thoughtful planning – planning valued social roles, understanding culture of workplace	Tier 3

Issue	Goals	Desired Outcome	Supports	System
			Skilled facilitation	Tier 3
			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 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 Will not be included 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

Issue	Goals	Desired Outcome	Supports	System
R&N support for family where participant lives with family	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 have the support they need to care 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 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	Tiers 1, 2 and 3
			Parent advocacy training	Tier 2
			Family advocacy support	Tier 2
			Connection to empowering disability networks	Tier 2
	To feel confident in their ability to access services and work with professional To feel themselves in control in selecting services and supports that meet the	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

Issue	Goals	Desired Outcome	Supports	System
	needs of their child and family 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		Professionals and services that assume capacity and work in person centred ways	Tier 2 capacity building for services
	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 overnight away from the immediate family	Families have succession plans	Succession planning seminars	Tier 3
			Support to strengthen informal support	Tier 2
			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
			Practical support	Tier 3
Systemic approaches		Communities are welcoming		LAC/ Local Government Community

Issue	Goals	Desired Outcome	Supports	System
		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
	   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
	   o Need for sexual expression often ignored
	• Home
	   o Most live in group accommodation
	• Health
	   o Deteriorating
	   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
	   o Preparing to retire
	• Social participation
	   o Less likely to be volunteering
	   o Less likely to be with peers
	   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
	Support memberships of interest based groups

Issue	Adults 55+
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 e.g. craft,
Working toward contribution	Expectations of contribution to others
	Enhance competences of role as family member, uncle, aunt
	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 - 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

Issue	Goals	Outcomes
		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
	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:	Families have succession plans

Issue	Goals	Outcomes
	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 advocate for services and supports for their family member and their family	Families know their rights and advocate effectively for their family member with disability.
	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	
	To feel confident in their ability to access services and work with professional	Families are able to gain access to desired services, programs, and activities in their community.
	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	
	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	Families experience health and wellbeing
	To be able to work as much as they want	

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 Australian Government and the Governments of all 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	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
			providers to account for movement toward outcomes	
Building a vision	Broaden views of what is possible Evidence about what leads to good outcomes Connect people to stories of 'ordinary lives' Mentor by like minded people	Tier 2 capacity building 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 capacity building 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	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.

What	What is required	Cluster	Positive	Challenge
		LAC where emphasis is on community and belonging		
	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 Valorisation)	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.
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 - seems inconsistent that this

What	What is required	Cluster	Positive	Challenge
				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 services related to behaviours of risk e.g. drug and alcohol	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.
Supported decision making (SDM)	Resource and training material targeted at people	Should be resources in Tier 2	Excellent resource material was	Supported decision making is very new. More prominence needs to be given to it because by

What	What is required	Cluster	Positive	Challenge
	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. - Sometimes requires cultural shifts to be sustainable.	15 009 Training in planning and plan management	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	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
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 23 022 – development 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 11006 Training for carers and others in	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	

What	What is required	Cluster	Positive	Challenge
		behaviour management strategies 08002: Co-ordination of supports	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 hospital - Medical emergency - Abandonme nt - Psychologic al deterioration - A community barrier	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	Would be value in more detailed descriptors Anecdotal observations in the Hunter suggest variable use of Co-ordination of supports.

What	What is required	Cluster	Positive	Challenge
- Loss of housing			basis to amend plan as required	
Becoming a volunteer	Trusted person assists the 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. See http://www.afford.com.au/employment/transition-to-retirement-sp-829?videoid=nQTfe-qVpFg	08 002: 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		Recognition that the process has to go 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 come with all the knowledge and skills required.

What	What is required	Cluster	Positive	Challenge
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 26000 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. 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.