

Promoting Independence for People with Disability

BRIEFING PAPER FOR THE NDIS INDEPENDENT ADVISORY COUNCIL

COUNCIL MEMBER: KURT FEARNLEY

WRITER: BELINDA EPSTEIN-FRISCH

Introduction

The tragic fact is that on all indicators, people with disability fare much worse than their peers in the general population. They are much less likely to be engaged in education, in work and in community and their families and carers are less likely to be engaged socially and economically and are more likely to be experiencing social isolation and poor health.

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

The NDIS provides the opportunity to turn this negative cycle around; its early intervention approach can reward capacity and initiative – people do not need to be fearful that their increased capacity, their increased independence will leave them high and dry without support. The NDIS aims to provide confidence that reasonable and necessary support will be adjusted to reflect changed circumstances.

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

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

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

Defining independence

In the context of disability, the concept of independence does not confine itself to such traditional criteria as living in one's own home, or being employed in an appropriate job. Rock

(1988) argues “*Independence for young people with disability means having choice and control of their life and their environment*”.

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.

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

The term independence for people with disability however often conjures up visions of being ‘fiercely independent’, of valiant efforts to achieve self-reliance with loneliness and isolation as the result. One of the basic needs of all people is to be valued and loved and ‘fierce independence’ seems quite counter to this other most profound need. In fact, 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, achieving autonomy, making decisions about one’s life and engagement in one’s community is best achieved in equal valued partnership with others, i.e. as interdependence.

Key themes in literature on independence

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

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

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

A number of studies identify family support (attitudes and material resources) as the single most important contributor to a young person being able to maximise independence and transition into adulthood. The general attitudes of society however continue to be a

barrier to independence whereby stereotypical assumptions and low expectations make people with disability feel invisible, not respected and excluded.

Independence in young people 18 to 25

A recent literature review from the University of Melbourne "*Young People with a Disability: Independence and Opportunity*" by Stokes, Turnbull and Wyn provides an excellent synopsis of research directed to the question of what factors impact on the opportunities for independence for young people with disability.

Changing social context for young people today

Bauman (2001) and Beck and Beck-Gernsheim (2002) identify the changing meaning of independence as family structures change and life course becomes de-standardised. They highlight the need for individuals to take personal responsibility for decisions in relation to actions over which they have little control. Young people have little choice but to learn how to live with new realities such as labour market unpredictability and the fragmentation of traditional pathways through education and work. Studies document the trend for young people to rely on family resources (social and material) until they are well into their twenties and to be forced to make decisions about things over which they have very little choice (Woodman, 2009).

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

Identity development

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

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

Social relations

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

Yueng, Passmore and Packer (2008) conducted a study of nine young adults with cerebral palsy to ascertain their views about citizenship. Whilst they were living in the community, they faced isolation and loneliness as a result of having limited social networks. Yueng et al noted that it takes a long time to develop social relationships and that a young person might have to

engage in an activity many times before they were recognised by others and social interactions began to occur. It was noted that opportunities to form social networks were often mediated and dependent on paid carers who may be more informed of duty of care than promoting social interaction. They stressed that simply having people in their lives (for example, paid carers) does not equate to having social networks and friendships.

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

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

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

Decision-making

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

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

Managing risk

Risk taking is seen as a developmental hallmark of typical adolescent behaviour. Ponton (1997) argues that risk behaviours can have benefits because they are associated with the development of independence and survival without the benefit of parental protection. It can also be argued that risk taking behaviour can help foster independence in adolescence and is viewed as assisting in identity formation (Le Breton 2004).

Sociological frameworks tend to focus on the conditions that place young people at risk showing there is a direct association between a young person's level of social support and the number of health risk factors they exhibit. Correspondingly, studies show that young people with disability are more likely to engage in risk taking behaviour.

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

Resources and supports

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

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

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

Attitudes

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

- Wanting to create opportunities for the young person while seeking to ensure he/she is safe
- Wanting to ensure the young person has a good life while wanting their own separate life
- Wanting to ensure the young person has a separate and fulfilling social life while wanting to be less involved in the social life themselves
- Wanting to maximise their child's potential while wanting to accept him/her for who he/she is.

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

Whilst some studies demonstrate positive attitudes and community inclusion of people with disability, negative attitudes have persisted and have been ranked as one of the most commonly mentioned external barriers to participation. Yueng (2008) also found that stereotypic assumptions, low expectations and misunderstandings about particular impairments impacted on young people.

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

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

Literature from other cohorts

Adults older than 25

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

Children and young people

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

Literature about promoting independence and self determination in children focuses on assisting the child to express choice, identify preferences, have some sense of control over

their environment and a sense of autonomy in the own lives. It is about helping a child know who she is, what she wants, and how to go about getting it. Some examples of self-determination in early childhood are choosing who to play with, where to create a block tower, or getting napkins from the drawer to help set the table for dinner.

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

There are few studies in this area but literature aimed at parents encourages independence, recognising that many children with disability are sheltered from taking risks. Parents are told that independence helps the child by teaching him/her that it is ok to make mistakes, learn from them and take responsibility for the decisions and choices they make.

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

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

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

See discussion in an ordinary life paper

Systemic barriers to independence

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

The vast majority of schools, both regular and special schools have a tendency to velcro staff to students creating learned helplessness and dependence and thwarting the development of natural networks of helpful friends. Whilst some students do need significant support, that support must be crafted very carefully in order to facilitate opportunities for other children to interact and assist where necessary. Enabling children with disability to learn to appropriately

ask their friend or classmate for assistance is a skill of independence that cannot be acquired if adults surround a child.

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

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

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

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

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

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

What might independence look like?

Many people with disability, especially people with high support needs are forced into grouped models of service provision on the basis of cost. These equations seldom take account of the cost to the individual and society of increased dependence and poor quality of life nor the high cost of maintaining capital associated with many grouped models.

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

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

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

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

In summary, assisting participants to move toward independence requires:

- An encouraging, enabling approach that inspires people to try, supports and rewards their efforts and provides a pathway, not a prescription or a stick.
- A recognition that asking and encouraging will often not be enough. Participants need assistance to identify adjustments required to life, to the expectations of others, to the way in which support is usually delivered to facilitate greater independence. If independence was easily achieved, in most situations the participant would already be independent in the specified domain of life.
- A recognition of the critical role of peers in promoting identity and providing role models for greater independence. The development of relationships with people without disability may be a necessary first step to increase expectations and provide age appropriate guidance.
- A recognition that too much paid support may inhibit the development of freely given relationships with ordinary people. Participants and their families may require targeted support to develop informal support.
- Identification of possible ways in which technology may facilitate less dependence on paid support.
- Supported opportunities for risk taking – supporting the participant to move gently beyond his/her comfort zone to facilitate a learning opportunity from a challenge. Much work may be needed with family and service providers to facilitate an opening in which a challenge may be possible.

- The implementation of conscious strategies such as Active Support in grouped living environments. This requires staff to provide just the right amount of assistance to enable service users to successfully take part in meaningful activities and social relationships irrespective of their degree of their intellectual and physical impairments. This approach means that a person might only take part in some parts of a task; they do not have to do it all or do it independently to be involved in some of it.

Domain	Independence measure	Strategies to promote independence
Choice and control	Identity formation	Recognize and respect multiple identities of each individual e.g. encourage people to see themselves, for example, as a young woman, a member of a choir, a beach lover, not just a person with disability
	Decision making	<p>Actively encourage the use of a framework for supported decision making such as the Victorian 7 principles (Vic. DHS 2012) of:</p> <ol style="list-style-type: none"> 1. I have the right to make decisions 2. I can make decisions 3. I might sometimes need help to make decisions 4. I might be able to make decisions about some things but not others 5. I can learn from trying things out 6. I might want to change my mind 7. I might make decisions others might not agree with <p>Encourage and support people to make daily life decisions – when to get up, go out, where to go</p> <p>In planning meetings, take steps to enable people to make big life decisions e.g. where they live, what work they do, the services they use</p>
	Self determination (have authority and are supported to direct and manage their own services)	<p>Help people to take steps to move along a continuum from:</p> <p>Other people direct and manage the services for the individual</p> <p>Learning to manage and direct their own services</p> <p>Supported to manage and direct their own services</p> <p>Able to manage and direct their own services</p>

Domain	Independence measure	Strategies to promote independence
Daily life	Increasing skills toward self sufficiency	Provide training to facilitate increased skill Provide support to decrease reliance on paid support
	Active choices around nature of assistance	Support people to make the adjustments required to choose who assists them, how they are assisted, when they are assisted and where they are assisted
	Travel without support on public transport	Provide travel training to assist use of public transport
Relationships	Existence of relationships with people outside family and paid staff	Support people to make the adjustments required to go out as an individual (not in groups) and to attend places at regular times to facilitate being known and valued
	Choice of relationships	Support people to choose who they have relationships with, how often they have contact with people and assistance to extend relationships if desired
	Pursue relationships in ways and frequency of choice	Support people to have contact when they choose and in ways that they choose
	Independence in interaction	Support people to spend time with a friend without staff or family being present
	Engage in safe sex	Provide people with training and support in sexual health
Home	Choice of home	Support people to actively choose the model of housing and support and who they live with and to actively plan to achieve this goal
	Control over support in the home	Support people to make the adjustments required to have control over who supports them, how they are supported, when they are supported and where they are supported, including when they get up and go to bed, what they eat, when they go out, with whom and where
Health and wellbeing	Self reliant in coordination of	Support people to take steps toward understanding the screening and services they need for good health and

Domain	Independence measure	Strategies to promote independence
	health related supports	assist them to make and keep appointments and implement recommendations from appointments
	Self reliant in maintaining a healthy lifestyle	Support people to take steps toward understanding elements of healthy lifestyle and making adjustments required for a healthy lifestyle
Education and training	Participation in course of choice	Support people to choose and be supported in a mainstream course over a course for people with disability Support people to choose and be supported in a course in their area of interest
Work and valued social roles	Nature of employment or valued social role	Support people to choose and be supported in - Open employment over sheltered employment - Valued social roles that demonstrate competence in the area of their choice
Social, community and civic participation	Nature of leisure activities	Support people to genuinely choose (as against from a menu of options) leisure interests and activities, the time and location of the leisure activity and their leisure partners
	Engagement in mainstream community groups	Support people to become actively involved community groups that reflect their interests Support people to actively participate in community discussion about issues of interest.
	Voting	Support people to understand the electoral system, to register and to vote

Conclusion

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

The literature review highlighted key strategies that promote independence: assisting people to develop their identities, supporting people to make decisions and strengthening families to build positive visions that guide toward independence. The research reveals that young people

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

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

The way forward

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

Independence in reasonable and necessary support

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

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

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

2. Take active step to reduce barriers

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

3. Recognise the critical importance of relationships

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

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

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

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

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

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

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

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

6. Ensure people are supported to make decisions

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

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

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

8. Demonstrate the value of and pathway to independence

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

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

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

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

Capacity building in relation to independence

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

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

References

- Australian Institute of Health and Welfare (2009b) *Carer National Data Repository Scoping Study Final Report* Canberra: AIHW
- Bauman, Z., (2001) *The Individualised Society*, Cambridge Polity
- Beck, U., & Beck-Gernsheim, E., (2002) *Individualisation*, Sage, London
- Bigby, C., & Bould, E. (2014). *Guide to visiting and good group homes*. Melbourne: Living with Disability Research Group, La Trobe University.

- D' Eath, M., & Walls, M., (2003) *Quality of life of young people with intellectual disability in Ireland* reported in Stokes, H., Turnbull, M., & Wyn, J., (2003)
- Disability Services Division, Victorian Dept. of Human Services, (2012) *Supported decision making: a guide to assist people with disability to make their own decisions*
- Dyke, P., Leonard, H., & Bourke, J., (2007) Issues paper related to ARACY workshop: *Leaving school: Maximising participation and life outcomes in youth with intellectual disability transitioning from secondary school to adult life*, reported in Stokes, H., Turnbull, M., & Wyn, J., (2003)
- Kehily, M., (2007) *Understanding youth: Perspectives, identities and practices*, Sage
- Le Breton, D., (2004) Risk taking behaviours among young people, *Bulletin de l'Academie Nationale de Medicine*, 188(8) pp.1313-1321
- Mirfin-Veitch, B., (2003) *Education for adults with intellectual disability (including transitions to adulthood): Review of the literature prepared for the National Advisory Committee on Health and Disability to inform its project on services for adults with an intellectual disability*, Wellington, National Advisory Committee on Health and Disability, Donald Beasley Institute
- Nayak, A (2008) *Exploring socialisation, identity and culture*
- Novita Children's Services, (2014) *Promoting independence and letting go*
- Pascall, G., & Hendy, G., (2004) Disability and transition to adulthood: the politics of parenting, *Critical Social Policy* 24(2) pp. 165-186
- PBS Parents <http://www.pbs.org/parents/education/learning-disabilities/fostering-independence-in-children/>
- Ponton, L., E., (1997) *The romance of risk: why teenagers do the things they do*. New York Basic Books
- Rock, P. (1988) Independence: What it means to six disabled people living in the community. *Disability & Society*, 3(1), pp27-35
- Stokes, H., & Tyler, D., (2001) *Planning for the future: the evaluation: Phase one of the pathways project in Victoria*, Victorian Department of Education, Employment and training, Melbourne
- Stokes, H., (2012) *Imagining Futures: identity narratives and the role of work, education, community and family*, Melbourne, Melbourne University Press
- Stokes, H., Turnbull, M., & Wyn, J., (2013) Young people with a disability: Independence and Opportunity: A literature review at http://web.education.unimelb.edu.au/yrclinked_documents/research_report39.pdf
- Wierenga, A., (2009) *Young people making a life*, Basingstoke, Palgrave/McMillan
- Woodman, D., (2009) "The mysterious case of the pervasive choice biography: Ulrich Beck. Structure/agency, and the middling state of theory in the sociology of youth, *Journal of Youth Studies*, 12 (3) pp243-256
- Yueng, H., Passmore, A., and Packer, T (2008) Active citizenship or passive recipients: How young Australians with cerebral palsy define citizenship, *Journal of Intellectual and Developmental Disability*, 33(1) pp.65-75