

Planning to facilitate opportunities enabled under the NDIS

Briefing Paper for Discussion on Planning

Council member: Joan McKenna-Kerr

Writer: Belinda Epstein-Frisch

Introduction

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

A great deal is required of the planning process. It must help a person think about their goals and aspirations and operationalize 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 their guide in this exploration will be a stranger from the NDIA.

A further 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. And because 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.

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

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

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

Expectations of a planning process

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

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

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

Approaches to planning with people with disability

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

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

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

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

- Values and beliefs that underpin social inclusion
- Investment in people and families
- A shift of authority, control and power from the system/organisation to the individual
- Partnerships with people and families
- Tailoring support to the person; and
- Dealing with structural barriers

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

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

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

Roles based planning provide a further development on person centred planning, marrying “the most beneficial components of person centred planning to the critical thought base associated with Social Role Valorisation and to best practices for improving social status, social inclusion and employment outcomes for marginalized populations.” (Ramsey, 2007,p4)

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

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

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

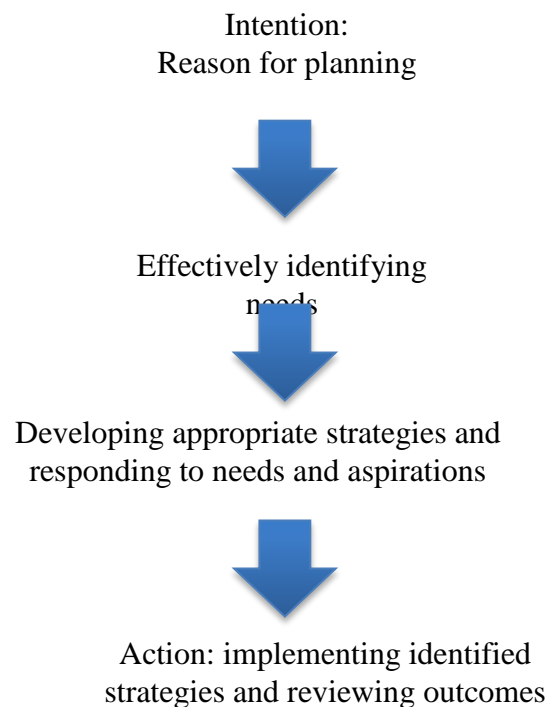
A review of best practice planning by Parsons, Cox and Williamson (2009) identified ten themes as organising principles for the discussion of best practice. The principles are:

- Person centred organizational culture
- Listening and giving credence to what the person with disability says
- Respect the natural authority of the person with disability and family
- Continuity of relationship and depth of knowledge of the person
- Focus on quality process and outcomes rather than tools
- Identifying real needs
- A developmental process underpinned by high expectations
- Safeguards
- Leadership and
- Flexible approaches

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

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

The framework is straightforward:



Intention

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

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

Effectively identifying needs

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

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

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

Developing appropriate strategies to respond to needs and aspirations

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

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

Action - Implementing the identified strategies and reviewing outcomes

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

Planning across the lifespan and in relation to particular population groups

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

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

Planning across life domains: connection with education

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

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

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

Collaboration between the NDIS and school planning could trigger plan reviews and new strategies related for example to transition between primary and secondary school, opportunities to broad the friendship circle and sense of belonging of a young person, subject choice and post school planning and the interplay of work experience and the casual part time jobs normative of many adolescents.

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

Observations of planning and the NDIS planning

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

In the absence of systematic study, anecdotal information from participants, families and NDIA staff indicates that within the constraint of the need for signoff of plans within a requisite period of time, the planning process and plan **may not** give sufficient focus to:

- Active participation of the person with disability, especially people with limited communication and that supported decision making is not in evidence
- Active facilitation of the inclusion of all significant others in the planning process
- Providing sufficient information and experience to enable informed decision making
- Helping people to think about how an aspiration can be pursued in ways that help the individual be seen as a valued and contributing individual while optimizing opportunities to develop friendships
- Helping people think about opportunities for engagement and challenge rather than filling a week with activities
- Identifying and strategizing ways to overcome barriers to success as well as the negative impacts of stereotypes

Anecdotally, the planning process goes well when people have thought about a vision for a meaningful life over an extended period of time and/or have engaged with a life planning process outside the NDIS. Where people come the NDIA overwhelmed by the active issues in their lives, seeing themselves in the role of client and service user, they need ideas and stimulus, ideally supported by trusting relationship before they can begin to dream of a life different from the one they have always known. This is more than can be sought from a few conversations with an NDIS planner.

An alternate approach

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

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

For these two groups of people, an NDIS budget for a package of supports can be negotiated within a short time frame. This should happen and be approved.

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

Recommendations

Council recommends that:

1. The NDIA differentiate between a funding plan and a life plan: a funding plan being the quantum of NDIS funds allocated to provide reasonable and necessary supports; a life plan being the plan for a participant to achieve their goals and aspirations.
2. That participants can choose to
 - a. Have the NDIA develop both their life and funding plans simultaneously; or
 - b. Elect for the NDIA to develop a funding plan based on current provision and agreed additional clear and present need as well as receive specific funding to purchase support to develop a life plan. The life plan will be submitted to the NDIA for a funding plan.
3. That additional work is prepared to scope and price the planning role.

Scheme sustainability if people develop a life plan outside the Agency

The danger with out sourced planning is that there will be significant variability with the interpretation of reasonable and necessary and plans will be developed that place scheme sustainability in jeopardy.

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

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

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

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

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

Similarly, participants will need to develop trust that the NDIS will adjust their support if and when their circumstances change. This may take some time to develop given that people have been schooled in a capped crisis driven system. However, just as when the NDIS undertakes the planning, the Agency will continue to have control of the size of the package that is ultimately allocated.

In summary, Council proposes that:

- The NDIA differentiate between a funding plan and a life plan: a funding plan being the quantum of NDIS funds allocated to provide reasonable and necessary supports; a life plan being the plan for a participant to achieve his/her goals and aspirations, maximise their participation and be included in the community.
- The current NDIA planning process is viewed as a funding plan process in which the participant is given an indicative budget (an estimate of their funding package based on what they are currently receiving and/or the reference package and money for any agreed additional clear and present need) as well as specific funding to purchase support to develop a life plan.
- The life plan is developed in an iterative process in the context of relationships with those with whom the person has ongoing connection.
- The life plan is then submitted to the NDIA for approval. Life-building infrastructure and coordination are included in the funding plan as an essential tool to support participants to implement their life-plans
- Following the determination of a reasonable and necessary funding package, the NDIA should devolve control and choice as to how the funds are spent (excluding illegal, income support or funding provided for equipment) to the individual.
- The Agency should develop a framework to address the above.

References

Community Living British Columbia (2009) *Addressing personal vulnerability through planning* accessed at <https://s3-ap-southeast-2.amazonaws.com/activ8wanda/Pearl/1046/Addressing%20Vulnerability%20through%20Planning%20-Pearl-1046.pdf>

NSW Dept. of Ageing, Disability and Home Care, (2009) *Exploring and implementing person centred approaches: A guide for NSW Community Participation program service providers*

Parsons, L., Cox, E. and Williamson, M., (2009) *A review of best practice in individual needs planning*, at www.nds.org.au/asset/view_document/979321556

Ramsey, S. (2007) Roles Based Planning: A thoughtful approach to social inclusion and empowerment. *The SRV Journal*, 2(1) p4-12

Sanderson, H., (2000) *Person centred planning: Key features and approaches*, <http://www.helensandersonassociates.co.uk>

Van Dam, T., Ellis, J., Sherwin, J., (2008) *Person centred planning: A review of the literature: Strengthening person centred planning in the Community Participation program*, NSW Dept. of Ageing, Disability and Home Care