

**Intellectual Disability Reference Group
of the Independent Advisory Council
of the National Disability Insurance Scheme**

Supports for decision making: Key issues

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Executive Summary

Purpose

To recommend changes to current NDIS policy and practice that will enhance support for decision making of people with cognitive impairment.

Key issues in context

Supported decision making is the term used internationally and across Australia to describe the process of providing support to people to make decisions and remain in control of their lives. Supported decision making starts from the premise that everyone has the right to participate in decision making and everyone draws on some support at some time to make some decisions.

Supported decision making draws on a support paradigm that acknowledges that the capacity to make decision grows and develops, that making decisions over the small things provides practice to enable bigger decisions; that not all decisions are of the same consequence and that capacity to make decisions is related to the nature of the decision and the nature of support. Ultimately, support for decision making is based on the premise that sufficient and effective decision making support compensates for difficulties in decision making. For many NDIS participants with intellectual or cognitive disability, decision making support will be reasonable and necessary to enable them to achieve their goals.

The concept of support for decision making is not well understood.

There are two key elements of support for decision making. The first element relates strategies to build the capacity of the person with disability to make or contribute to the making of decisions. The second element relates to strategies that increase the capacity of 'informal supporters' (i.e. family, friends and service workers) to provide the encouragement, opportunity and practice that contribute to enabling the person to make decisions and make it more likely that the decisions reached reflect the 'right' decisions. For a small but significant group of people with disability who have no one in their lives effectively able to support them to make decisions, the supporters must be intentionally recruited and assisted to have the skills and insights necessary to support the person to make or contribute to the making of decisions.

Currently decision making for most people with cognitive disability relies on informal arrangements where decisions are made by others, often in the person's 'best interests' and may not consider or include the person's will and preferences or opportunities to try new experiences. For most, the decisions made by informal supporters reflect the constraints of

the time, place, context and government funding (including low expectations and a focus on safety and avoiding risk). They reflect a period in which there was little choice and no control and hence the preferences, interests and life opportunities of the person with disability were forced into competition with those of family members. The voice of families and services were privileged without looking at possible conflicting interests. Little interest was paid to the voice, views and preferences of the person.

For some, the right to make decisions is removed under guardianship with jurisdictions continuing to use 'best interest' as the basis for decision making.

Currently supported decision making does not exist in a legal framework in Australia. This is because there is no provision for the legal recognition of, for example, shared decision making or standing for supporters.

Even the language used to describe strategies to assist people with disability to make decisions is undecided. The Australian Supported Decision Making Network¹ proposes the development of a National Framework including the establishment of consistent language to underpin consistency of participation and practice. Ultimately the NDIS should adopt the language of the National Framework. In the meantime however, the IDRG uses the term 'support for decision making' on the basis that it as a term used to describe a practice framework, thereby distinguishing itself from legal frameworks that may or may not be passed in Australia.

Article 12 of the UNCRPD and the aspirations of the NDIS Act compel the NDIA to take steps to support the decision making of participants. Practice overseas and in Australia tells us that there are many elements of support for decision making that can be implemented within current legal frameworks.

This report describes the new paradigm of support for decision making distinguishing it from current practice.

"The core concepts of supported decision making are a shift from the best interests model of support and substitute decision making to a model of support based on enhancing a person's skills and experience to make decisions, express their will and preference and the acknowledgement that part of the supporter's role may be to interpret the individual's will and preference" (Bigby & Douglas, 2016, 6).

¹ A network set up in 2012 to facilitate the implementation of supported decision making in Australia. The ASDMN has more than 80 members including people with disability, families and members involved in service delivery, advocacy, government and academics. Government members contribute on the basis that their input is not taken to commit their government to a particular course of action.

This report identifies the main barrier to support for decision making in the lack of information, experience and confidence of supporters that the person with disability can make or contribute to the making of decisions. This is balanced against strong enablers in the UNCRPD, Australian pilot projects and research and the new Australian Supported Decision Making Network all of which are providing guidance in relation to emerging practice.

The challenge for the NDIS is:

“ensuring they (participants) have support to enable them to participate in decisions – at the preplanning, planning, implementation stage of their plans and in their day-to-day lives. This means not only understanding the processes of good support for decision making but also recognizing the role of decision making supporters and developing their skills” (Bigby & Douglas, 2015:3).

While there is a growing body of research, best practice that clarifies the way through the dilemmas and tensions in different circumstances is yet to be articulated.

The IDRG including the foremost Australian researcher in the field believe, however, that enough is known about what works for the NDIA to develop interim operational guidelines for strategies to support people with cognitive disability to make decisions about their plans and about their lives.

This paper, prepared by the Intellectual Disability Reference Group, explores several dilemmas and issues in greater depth and recommends ways to progress support for decision making within the NDIS.

The nature of support for decision making

Understanding and applying the emerging evidence is a key challenge for the Agency, compounded by the fact that support for decision making is a process that takes time and can look very different in practice for different individuals. The rapid growth in the number of participants at surge together with the limited early roll out of the ILCB means that few resources will be available to support the process. This will represent a gap in provision for many participants if not addressed.

Promotion of support for decision making

Many people are completely unaware of the concept and process of support for decision making. A systematic approach to raising awareness and providing targeted information is required for people with disability, families, informal supporters, NDIA and outsourced staff and service providers. Consistent messages that address the varied interests and challenges of different audiences including audiences ‘on the margins’ will need to be crafted.

Capacity building for participants and supporters

There is little capacity building for participants and supporters in relation to decision making. Some resources are available online but in general they are underutilised. Services and supports will not be available in the ILCB for some time and the ILCB Commissioning Framework has no provision for prioritising one form of capacity building over another. This leaves the possibility that support for decision making may not be available through the ILCB in all areas and looms as an issue of critical importance.

Allocation of support for decision making in the preplanning, planning and plan implementation processes

Staff involved in planning will have a key role in identifying the type and adequacy of current decision support of participants and potential participants. Developing effective processes that staff can use within the constraints of surge and the limited early roll out of the ILCB are significant challenges for the Agency that need to be addressed urgently.

The paper identifies the most vulnerable participants and proposes a pragmatic pathway forward. The most vulnerable participants are seen as those who live in closed systems such as group supported accommodation, lack effective informal support and have no unpaid supports in their lives, are involved in fundamental life changes in their first plan (e.g. moving out of an institution), are connected to the criminal justice or child protection systems, have different views to their family / informal supporters and have families whose views are in conflict with principles of NDIS.

Nominees

The NDIS nominee provisions attempt to bridge the supported and substitute decision making regimes and as such the NDIA will need to provide clear guidance as to how nominees can support decision making. Without this type of contextualisation, NDIS nominee provisions could be a form of substitute decision making that would diminish the choice and control of NDIS participants rather than enable them to have greater choice and control over their lives.

The NDIA rarely appoints nominees despite having the capacity to do so. While this might seem consistent with minimal formal intrusion on participants' rights to make their own decisions, in practice it usually leaves substitute decision making by informal supporters in place without the requirements and safeguards outlined in the NDIS Nominee Rules. In many of these situations, education, mentoring and peer support will assist informal supporters to provide effective and accountable support for decision making. However where no effective informal support exists, the availability of supporters for decision making presents a challenge.

The issue of the source of support for decision making is relevant. The NDIS rules leave open the option of service providers providing support for decision making; guardianship is sometimes pursued and trial sites often use Support Coordination and Intensive Support Coordination as part of assisting a participant to make big life decisions. The differential use of nominee provisions, Support Coordination and Guardianship warrants discussion.

Decision making for children and young people under 18

Parents work with the NDIA on behalf of most children and young people. Challenges occur where parents are not willing or able to fulfil their obligations under the NDIS legislation or where they make planning decisions for their child that are inconsistent with the objects and principles of the NDIS Act. Providing support for decision making for children with disability in care is another challenge.

Market failure in relation to support for decision making

Across the disability sector, there is currently very limited understanding of support for decision making. This is the case particularly for providers of core supports whose staff should support decision making in people's day to day lives. Even in capacity building organisations, understanding of support for decision making is variable.

Research coordination to build an evidence base

Trials of different ways of delivering support for decision making are in train or have taken place in NSW, Victoria, South Australia and the ACT. From these we will gain insights into sources for recruitment of supporters, training and support requirements and a framework to distinguish support for decision making from informal supporters through to formal substitute decision making. A number of tools and resources were developed using the NDIS Practical Design Fund and an ARC Linkage Grant over four (4) years will enable a randomised control trial to see whether an evidence based training program changes the practice of supporters of decision making.

Research coordination is essential to understand the emerging evidence and operationalize good practice at scale. The NDIA may well have a role in supporting the development of accessible research so that participants, families, services and the NDIS become consumers of research, better able to make evidence based decisions.

Recommendations

Recommendations in relation to the nature of support for decision making:

That the Agency:

1. Develops a set of practice guidelines for support for decision making in the NDIS based on the National Decision Making Principles outlined by the Australian Law Reform Commission.
2. Strengthens its relationship to researchers to ensure the emerging evidence base strengthens and informs:
 - Capacity building in the ILC
 - The work of Support Coordinators
 - Items in the Support Catalogue
 - Support in packages of reasonable and necessary support.

Recommendations in relation to promotion of support for decision making

That the Agency:

3. Co-designs and promotes information about supported decision making targeted to the varied audiences.
4. Ensures that the issue of support for decision making is addressed in preplanning sessions and all capacity building activities funded through the ILCB.
5. Ensures that the ILCB Commissioning Framework includes support for decision making as one of the key deliverables of funded services.
6. Builds requirements in relation to support for decision making into the provider registration process.

Recommendations in relation to capacity building for people with disability and supporters

That the Agency:

7. Ensures that the ILCB Commissioning Framework includes support for decision making as one of the key deliverables of funded services.
8. Provides support for decision making in the plans of participants especially where capacity building in relation to support for decision making is unavailable or likely to be insufficient in the ILCB.

Recommendations in relation to the allocation of support for decision making

That the Agency

9. Ensures that Agency and outsourced staff who undertake planning activities can identify the effectiveness of current decision making processes and describe, recognise, demonstrate and foster good support for decision making practice for participants.
10. Adopts a pragmatic approach to support for decision making during surge whereby:
 - The concept and practice of support for decision making is emphasized in preplanning workshops and interaction with the LAC
 - Capacity building training and resources are readily available through the ILCB. This includes skill building opportunities for participants and a range of potential supporters
 - In areas in which participants transition into the NDIS prior to the roll out of the ILCB, that the NDIA runs or facilitates the running of information and capacity building sessions to enhance support for decision making of people with cognitive impairment.
 - The most vulnerable participants are prioritised to receive funded supports for decision making as part of their first preplanning and plan preparation processes, i.e. prior to the preparation of the first plan.
 - Funded supports to build capacity for decision making (for both the participant and their supporters) are included in the packages of participants with cognitive impairment to ensure that at the second planning conversation, support for decision making follows a more effective and accountable process. These resources are provided on an opt-out basis.
11. Recognises the most vulnerable participants as those who:
 - Live in closed systems such as group supported accommodation or
 - Lack effective informal support and have no/few unpaid supports in their lives or
 - Are involved in fundamental life changes in their first plan (eg moving out of an institution) or
 - Are connected to the criminal justice or child protection systems or
 - Have different view to their family / informal supporters or
 - Have families whose views are in conflict with principles of NDIS
12. Recognises that some participants will require ongoing support for decision making in order to uphold their human rights and meet the requirements of the NDIS Act.
13. Articulates more clearly the purpose and parameters of the Support Coordination roles including to assist participants to enhance their:
 - Capacity to make decisions
 - Self efficacy, self management and empowerment
 - Personal safeguards.

Recommendations in relation to nominees

That the Agency:

14. Works toward a best practice approach to the issue of nominees including:
 - The provision of maximum support to participants to increase/improve their ability to make decisions
 - The provision of capacity building for informal supporters to support the person to make decisions and be more accountable to the person
 - Establishing new guidelines on when it should appoint a nominee taking account of the dangers of unregulated informal substitute decision making. Arguably, a nominee should be appointed whenever, despite maximum available support, a participant lacks the ability to make NDIS plan decisions,
 - The Agency satisfying itself that any proposed nominee is appropriate.
 - The Agency ensuring that best interests based substitute decision making is not in fact occurring where a nominee has not been appointed.
 - The funded supports in the participant's plan should include:
 - Support to develop his/her decision making ability
 - Support to develop the ability of informal supporters and nominees to provide support for decision making
 - Where a nominee is appointed, the participant plan include detail on how the nominee will support the participant to develop decision-making skills
 - The Agency reviewing the need for and appropriateness of nominee arrangements as part of each plan review
 - Information and capacity building opportunities in relation to support for decision making be a strong focus of the ILCB.
15. Makes changes to the nominee rules and operational guidelines to ensure that nominees are educated about the primacy of the person's will and preferences and understand how to operationalise their role with respect to the participant's "personal and social well being" in a rights based framework.²
16. Develops guidelines to distinguish the different circumstances giving rise to the use of nominee provisions, Support Coordination and Guardianship.

Recommendations in relation to decision making for children and young people under 18

That the Agency:

17. Includes a focus on children and their parents in all NDIA activities aimed at developing support for decision making

² The framework for support for decision making (Bigby and Douglas, 2015, 15) assists a supporter to identify and describe the decision in ways that retain will and preferences as the primary focus while guiding the supporter to take account of scope, who is involved, consequences, constraints and time frames

18. Includes a focus on the importance of assisting children and young people to develop decision making skills in all material aimed at parents of children and young people. Like other life skills, support for decision making would benefit from starting early which would allow the child with cognitive impairment to develop confidence and skills with decision making as their peers do
19. Develops protocols to guide staff in ensuring there is an appropriate person to represent the child where, despite maximum available support, parents are not making appropriate NDIS planning decisions for their child. That the protocols are developed jointly with the Children with Disability Australia (the peak advocacy body for children), other key advocacy groups and family leaders
20. Ensures that the delegate for decision making for children in care has a first hand relationship with the child.

Recommendations in relation to market failure

That the Agency:

21. Develops an item in the Support Catalogue related to support for decision making including
 - A role description for supporters of decision making
 - An outline of the skills, competencies and personal characteristics required for a DM supporter
 - An outline of the core topics for training for supporters of decision making
22. Commissions capacity building in support for decision making in the ILCB. This should include training and mentoring for supporters of decision makers as well as assisting families, carers and services to support decision making.
23. Builds requirements in relation to demonstrating support for decision making into provider registration processes.
24. Undertakes a targeted registration process to encourage user led capacity building organisations to register in the Assist Life Stages Transition cluster to provide training and support for decision making and Support Coordination.

Recommendations in relation to the coordination of research

That the Agency:

25. Works together with lead researchers in support for decision making to ensure that NDIA practice is consistent with emerging evidence.
26. Encourages and assists researchers to disseminate their research in forms that are accessible to people with cognitive impairment and their families.
27. Develops and implements a model for the disseminating research to enable staff, participants and families to be more competent consumers of research, able to distinguish evidence based resources.

Recommendation in relation to terminology

That the Agency:

28. Uses the term 'support for decision making' pending finalisation of the National Supported Decision Making Framework.

Introduction

Supported decision making is used internationally and across Australia to describe the process of providing support for people with disability to make decisions and to remain in control of their lives.

Decision making is usually seen as a skill that grows and develops as a result of encouragement, opportunity and practice over many years. It is a normal part of child development. Children start by making small day to day decisions such as what to wear, what to eat for breakfast and over time and with support, they are able to grow in capacity to make decisions of greater consequence. Unfortunately, many adults with cognitive impairment have had little opportunity to make choices and determine personal direction and as a result, their capacity to make decisions has not developed.

The developmental approach to decision making is common sense. It acknowledges that making decisions over the small things provides practice to enable bigger decisions; that not all decisions are of the same consequence and that capacity to make decisions is related to the nature of the decision and the nature of support. In promoting the right of all people with disability to make decisions, the NDIS must provide a framework and resources to ensure that the assistance given to vulnerable people to support them to make decisions, is evidence based and promotes wellbeing.

The concept of support for decision making is not well understood. There has been very limited support to assist informal supporters to understand the new paradigm or strengthen their capacity to bring forward the voice of their family member with cognitive impairment. While resources for families encourage them to have raised expectations of/for their family member, the concept of capacity has largely been avoided. Supporters however have lacked guidance and examples of how to give voice to and support the decision making capacity of the person with disability. By default, this enables informal supporters scope and authority to make decisions 'in the person's best interests' (i.e. substitute decision making).

There are two key elements of support for decision making. The first element relates to the person with disability where support for decision making requires capacity building to enable the person to make or contribute to the making of decisions. The second element relates to the supporters of the people who are making decisions. In general, supporters are the person's informal network of family and friends. Support for decision making involves increasing their capacity so that they provide the encouragement, opportunity and practice that will contribute to the capacity building of the person and make it more likely that the decisions reached reflect the 'right' decisions. It also involves staff from services supporting people in ways that build their capacity and support their decision making.

For a small but significant group of people with disability who have no one in their lives effectively able to support them to make decisions, the supporters must be intentionally

recruited and assisted to have the skills and insights necessary to support the person to make or contribute to the making of decisions.

Current practice

Decision making for most people with cognitive disability relies on informal arrangements where decisions are made by others, often in the person's 'best interests' and may not consider or include the person's will and preferences or opportunities to try new experiences. For most, the decisions made by informal decisions makers reflect the constraints of the time, place, context and government funding (including low expectations and a focus on safety and avoiding risk). They reflect a period in which there was little choice and no control and hence the preferences, interests and life opportunities of person with disability were forced into competition with those of family members. The voice of families and services were privileged without looking at possible conflicting interests. Little interest was paid to the voice, views and preferences of the person.

For some, the right to make decisions is removed under guardianship with jurisdictions continuing to use 'best interest' as the basis for decision making.

Current practice that enables informal supporters and legally appointed guardians to remove the right to make decisions is in conflict with Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which states that persons with disabilities enjoy legal capacity on an equal basis as others in all aspects of life. In signing the UNCRPD, the Australian Government committed to develop "appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity" (UNCRPD 2006).

The term 'supported decision making' describes both practice and legal³ frameworks. This paper uses the term 'support for decision making' to refer to those elements of supported decision making that can be implemented now within the current Australian legal context.

A new paradigm

Support for decision making involves providing sufficient and effective support to compensate for difficulties a person might have with decision making. This can include:

³ Under Australian law, the right to make decisions is often conflated with a person's mental capacity (decision making skills). When there are doubts about someone's mental capacity (e.g. in understanding implications of decisions), their legal capacity is frequently overridden or removed through guardianship (a substitute decision maker). In such situations, decisions are guided by consideration of what is deemed to be in a person's 'best interests' and may or may not include consideration of their will and preferences.

- Changing others' expectations
- Developing a person's skills, experience and confidence
- Providing information in a format that is better understood by the person
- Supporting a person to express their will and preferences
- Sometimes interpreting the person's will and preferences
- Support tailored to the individual and their situation.

As such, this new paradigm recognises that support varies in type and intensity depending on the person, the context and the type of decision.

"The core concepts of supported decision making are a shift from the best interests model of support and substitute decision making to a model of support based on enhancing a person's skills and experience to make decisions, express their will and preference and the acknowledgement that part of the supporter's role may be to interpret the individual's will and preference" (Bigby & Douglas, 2016, 6).

Barriers to support for decision making

Support for decision making is predicated in ensuring opportunities for decision making supporters to understand and apply processes that develop the capacity of the person. A common barrier to decision making arises however when supporters lack information, experience and confidence that the person (especially those with significant cognitive disability) can be supported to make decisions or even contribute to making them. This often includes families and significant others as well as service providers.

A recent major study by Bigby, Whiteside & Douglas explored this lack of confidence by examining the processes and dilemmas associated with supporting people with cognitive disability in decision making. The study found that while participants⁴ mostly supported the broad concept of supported decision making, "supporters saw this as a complex, dynamic and frequently chaotic process" (Bigby, Whiteside & Douglas, 2015, p1). Relationships and tailoring support to each individual and each situation were fundamental to success alongside skills and knowledge that included communication skills, self awareness, a capacity for reflective discussion, conflict resolution skills and knowledge of strategies to decision making processes to each individual. The study also examined multiple dilemmas and tensions associated with supporting a person with cognitive disability to make decisions.

⁴ People with cognitive impairment with experience in being supported to make decisions and people with experience in supporting someone with cognitive disability to make decisions

Enablers of support for decision making

The UNCRPD, Australian pilots and research as well as the formation of the new Australian Supported Decision Making Network are enablers of support for decision making stimulating the development and sharing of emerging practice.

Article 12 of the United Nations Convention on the Rights of Persons with Disability (UNCRPD) recognises that people with disability have legal capacity and legal standing affirming people's right to make decisions in their lives and throwing into question the consistency with human rights of current guardianship provisions across Australia. In 2014, the Australian Law Reform Commission gave voice to Article 12 when it proposed that *"the will, preferences and rights of persons who may require decision making support must direct decisions that affect their lives"* (ALRC, 2014, para 3).

Article 12 is reflected in the Australian Law Reform Commission National Decision Making Principles proposed to underpin reform to Commonwealth, State and Territory laws (Australian Law Reform Commission, 2014). The principles are:

Principle 1: The equal right to make decisions: All adults have an equal right to make decisions that affect their lives and to have those decisions respected.

Principle 2: Support: Persons who require support in decision making must be provided with access to support necessary for them to make, communicate and participate in decisions that affect their lives.

Principle 3: Will preferences and rights: The will, preferences and rights of persons who may require decision making support must direct decisions that affect their lives.

Principle 4: Safeguards: Laws and legal frameworks must contain appropriate and effective safeguards in relation to interventions for persons who may require decision making support, including to prevent abuse and undue influence.

Australian research and pilot initiatives are important enablers of support for decision making. La Trobe Living with Disability Research Centre is a foremost centre for research into supported decision making and has completed several pilot studies with additional funded pilots and research projects underway. Pilot projects in NSW, Victoria, Queensland and South Australia have and are testing practical models of support for decision making including pilot programs in some NDIS Trial Sites. These include testing different approaches to:

- Recruiting volunteers
- Developing capacity of people with cognitive impairment
- Supporting families, friends and frontline support staff
- Using paid/professional supporters

- Formal agreements (e.g. Canada: representation agreements and microboards)

In addition, a 4 year ARC grant aims to produce and test evidence based education resources aimed at boosting the ability of decision supporters to put the person's desires and values at the centre of decisions. The project will investigate the impact of the innovative education resources on the practices of decision making supporters and the person being supported in a randomized control trial in Victoria, NSW and Queensland.

The Australian Supported Decision Making Network (ASDMN) is another driver of change. Established in 2012 to facilitate the implementation of supported decision making in Australia, the ASDMN has over 100 members including people with disability, families, service providers, advocates and people who work in government. It has become a hub of expertise because of members' association with trial projects. The Network is leading work to develop a Supported Decision Making Framework that will include the establishment of:

- Consistency of language to underpin consistency in practice and participation
- Safeguards for the Supported Decision Making (SDM) process, for people using SDM and for supported decisions
- Capacity building resources and principles for funding supported decision making
- Mechanisms to facilitate innovation and continuous improvement
- Community capacity building acknowledging that everyone has responsibility to enable decision making where and when it is needed.

The role of the NDIS in support for decision making

The UNCRPD and the NDIS Act set an imperative for action to support people with cognitive disability to make or contribute to the making of decisions that affect their lives. The NDIS Act highlights the responsibility of the Scheme *"to give effect to Australia's obligations under the Convention of the Rights of Persons with Disabilities"* (Object 3(1)(a)) including the responsibility to develop appropriate measures to provide access by persons with disability to the support they may require in exercising their decision making capacity. Support for decision making is inferred in the NDIS's responsibility *"to enable people to exercise choice and control in the pursuit of their goals and in the planning and delivery of their supports"* (Object 3(1)(e)).

The challenge for the NDIS is:

"ensuring they (participants) have support to enable them to participate in decisions – at the preplanning, planning, implementation stage of their plans and in their day-to-day lives. This means not only understanding the processes of good support for decision making but also recognizing the role of decision making supporters and developing their skills" (Bigby & Douglas, 2015:3).

While there is a growing body of research, best practice that clarifies the way through the dilemmas and tensions in different circumstances is yet to be articulated.

However, the IDRG including the foremost Australian researcher in the field believe that enough is known about what works for the NDIA to develop interim operational guidelines for strategies to support people with cognitive disability to make decisions about their plans and about their lives.

This paper, prepared by the Intellectual Disability Reference Group, explores several dilemmas and issues in greater depth and recommends ways to progress support for decision making within the NDIS. This report was passed by the IAC at its meeting in May 2016. Subsequent discussion led to the recommendation that the target group be extended to people with cognitive impairment because the content and recommendations were seen as appropriate for this broader group.

Issue 1 The nature of support for decision making

Inquiry and research

There is increasing acceptance that sufficient and effective support assists people with cognitive impairment to overcome difficulties in their decision making through the changed expectations of others, the development of an individual's skill and experience and the provision of support to express their will and preferences (sometimes via the interpretation of supporters) in ways that takes account of the nature of the decision and the individual situation.

Academic work by Bigby and Douglas at La Trobe University has distinguished between:

- 1) Models for delivery of support for decision making i.e. how to identify and support supporters. Models of support include circles of support, microboards, representation agreements, recruiting and matching volunteers, supporting 'supporters' either newly recruited and matched or simply existing informal supporters.

Bigby and Douglas are currently reviewing the evaluations of all Australian pilots and in time will be able to articulate an emerging evidence base in relation to models of support.

- 2) The actual practice of support for decision making i.e. the actual processes of providing support, addressing the question of how a supporter provides support for decision making to a person. This work examines the process irrespective of the model of support or status of the supporter e.g. whether part of formal program, a family member, paid facilitator, guardian, supporter, service provider etc.

Bigby and Douglas have developed a framework for practice and training modules. An ARC Linkage Grant will enable a randomised control trial to see if the training

changes practice of supporters.

Frameworks for practice (developed by Bigby, WA Individualised Services and others) guide supporters in sorting decisions (by scope, who is involved, constraining influences and consequences) and steps for practice. Their practice is underpinned by National Decision Making Principles outlined by the Australian Law Reform Commission (2014).

Current approach

In April 2015, COAG Disability Reform Council agreed that NDIS fund decision supports.

The NDIS Service Delivery Operating Model (SDOM) identifies the LAC role as the main point of contact for most participants. Although the LAC case load will be large, LACs will have the opportunity to get to know people better than planners.

Information about support for decision making is not currently discussed in preplanning sessions. In all NDIA and outsourced planning however the participant is meant to be at the centre of the planning process with family and friends seen in a consultative role. There is some doubt however as to whether these good intentions always translate into good consistent practice.

In Barwon, in complex situations where there are differing views between the participant and the family especially in relation to housing, relationships and decision making, the NDIA takes additional steps to enable the voice of the person with disability to be heard. The additional steps include allocating the participant to the intensive stream for planning and providing Support Coordination in the plan. On occasion, assistance is also sought from advocacy agencies, from the Office of Professional Practice and from a guardianship hearing.

In less complex situations in which the participant has no effective informal support, Support Coordination (with a strong capacity building intention) is included in the plan.

Some advocates and service providers proactively identify the need for and provide support for decision making.

Challenges

Emerging research must influence practice.

Staff undertaking a planning function need to question if and what type of support for decision making the person has and determine whether additional support is required.

Families are unfamiliar with support for decision making.

The Support Coordination role is not well understood by providers who often reduce the role to case management.

Recommendations p7

Issue 2: Promotion of support for decision making

Current practice

There is little understanding of support for decision making among all stakeholders.

There is currently very little information available to people with disability, families, carers and service providers about approaches to support for decision making.

Challenge

To provide targeted information for people with disability, families, informal supporters, NDIA and outsourced staff and service providers with consistent messages that address the varied interests and challenges of different audiences.

Recommendations p8

Issue 3: Capacity building for people with disability and supporters

Current practice

Capacity building needs to focus on how to support decision making for individuals with cognitive impairment and how to build the capacity of supporters. There are few resources directed at building the capacity of participants or supporters in the area of support for decision making. Some are online but are under utilised. It is of interest to note however that small trials of supported decision making conducted in NSW (NSW Department of Family and Community Services, 2015) and Victoria (Burgen and Chesterman, 2015) found tools and formal resources alone were not helpful in shaping practice. It is unclear whether this was because of the tools offered or that tools more generally do not greatly assist the dynamic nature of the supported decision making process.

There is very little recognition of the need for accountability of informal supporters to the person they are supposed to be supporting.

There are a number of practice models and tool kits and resources identified in the bibliography that focus on how a supporter (from whatever source) provides support for decision making for a person. Most are associated with small pilots and pieces of research.

Challenges

Resources and support will not be available in the ILCB for some time and the ILCB Commissioning Framework has no provision for prioritising one form of capacity building

over another. This creates the possibility that support for decision making may not be available through the ILCB in all areas.

Recommendations p8

Issue 4 Allocation of support for decision making in the preplanning, planning and plan implementation processes

Current practice

Support for decision making currently has a very low profile in the preplanning, planning and plan implementation processes.

Challenge

Breaking the assumption that participants have actively chosen their current options.

Allowing time frames for planning that recognise the long time frame required for effective support for decision making to occur in some situations.

Finding suitable people to support participants to make decisions

Identifying which participants require support for decision making as a priority

Developing a process that works within the constraints of surge and the limited early roll out of the ILCB.

Recommendations p8

Issue 5: The appointment and training of nominees

Legislative requirements

The NDIS (Nominees) Rules indicate that:

- People with disability are presumed to have capacity to make decisions that affect their lives. Appointment of a nominee will only be justified when it is not possible for a participant to be assisted to make decisions for themselves.
- The NDIA has to take into account a range of factors in deciding who to appoint as nominee, including any wishes of the person, whether a proposed nominee is equipped for the role and whether there is any conflict of interest. If a person has a guardian with relevant functions appointed under State or Territory law, the guardian is presumed to be the appropriate nominee.

- A nominee cannot be an NDIA staff member. However, there is no legal bar on appointing another service provider as nominee - either an individual or an organisation. A nominee has to avoid or manage any conflict between their interests and the interests of the participant and inform the NDIA of the conflict. Being a service provider automatically creates a conflict of interest.

Duties of a nominee include ascertaining the wishes of the participant, acting in a manner that promotes the personal and social wellbeing of the participant and only making a decision for the participant if the nominee considers the person is not capable of making it (S78 and S80 of *NDIS Act, 2013*).

In addition, the nominee has a duty to build the participant's ability to make their own decisions and it is expected that the Agency will assist nominees in fulfilling this duty (Nominee Rules Para 5.10 and 5.11).

Current practice

To date, the NDIA has very rarely appointed a nominee. Instead where no informal decision making processes are in place, the Agency uses Public Guardians (where they have been appointed), advocacy when available and otherwise funded supports to provide intensive planning that involves big life decisions (WA use providers who use Personal Futures Planning, Victorian planners use Person Centred Planning planners). All sites have a range of communication tools developed externally by specialists in this area. NT/ SA have tools that are culturally appropriate for ATSI.

Positive features and challenges of the NDIS nominee provisions

The requirements that the nominee builds the capacity of the person with disability to make decisions, that the Agency assists nominees in fulfilling this duty and monitors the action of nominees are positive.

Some of the challenges of the NDIS nominee provisions arise from their attempt to bridge the substitute and supported decision making regimes.

One of the key differences between a substitute decision making regime and a supported decision making regime is said to be that substitute decision making is based on "what is believed to be in the objective 'best interests' of the person concerned, as opposed to being based on the person's own will and preferences."⁵ However, some substitute decision making regimes, such as the ACT guardianship legislation, are based on the decision maker seeking to make the decision the person would have made if able. The ALRC has recommended a similar approach in its recent report.

⁵ UN General Comment (p.6).

When the Nominee provision in the NDIS Act state that the duty of the nominee is to promote ‘the personal and social wellbeing of the participant’, it requires the nominee to make a judgement regarding what they consider will lead to the personal and social wellbeing of the person. While the nominee has a duty to *ascertain* the wishes of the participant, any actions they take must *promote* the person’s wellbeing. Without a nuanced understanding of wellbeing that is rights focused rather than paternalistic, the nominee provisions could inadvertently undermine the legal capacity of NDIS participants.

Challenges in NDIA practice

NDIA nominee provisions require a clear explanation as to how supported decision making could be used by nominees. Without this type of contextualisation, NDIS nominee provision could be a form of substitute decision making that would diminish the control and choice and well being of NDIS participants rather than enable them to have greater choice and control over their lives and otherwise lead lives consistent with the objects and principles of the NDIS Act

Nominee provisions have been interpreted as a last resort provision. Whilst it appears that current NDIA practice involves minimum formal intrusion on participants’ rights to make their own decisions, it is likely that substitute decision making is in fact occurring on an informal basis for a high proportion of participants with cognitive impairment. This is without the requirements and safeguards spelt out in the nominee system including the need for the Agency to be satisfied as to the appropriateness of the nominee, to monitor the actions of the nominee (a commitment with significant resource implications for the NDIA) and for the nominee to build the capacity of the person with disability to make decisions.

In a high proportion of cases, family members will be appropriate nominees and education, peer support and mentoring will enhance their capacity and accountability as nominees. In a small proportion of cases, families and informal supporters will not be appropriate and it will often be very difficult to find a suitable nominee except through appointment of a guardian which immediately moves it into the realm of substitute decision making.

The NDIS Rules leave open the option of existing service providers as nominees but this option should be approached with great caution. Whilst it is acknowledged that service providers should provide support with daily decision making, it would never be appropriate to appoint a provider of core supports as nominee. Trial sites’ practice often involves the use of funded Support Coordination and Intensive Support Coordination where participants lack informal decision making supports and significant life decisions are required.

The willingness and appropriateness of advocates to act as nominees requires exploration.

The differential use of nominee provisions, Support Coordination or guardianship warrants discussion.

Recommendations p9

Issue 6: Decision making for children under 18 years of age

Current practice

For children (including young people up to age 18), the person or persons who have 'parental responsibility' work with the NDIA on behalf of the child. This is so unless the NDIA is satisfied that:

- A child is capable of making their own decisions and it is appropriate that the child be allowed to do so, or
- Someone other than a person with parental responsibility should represent the child. In making this decision, the NDIA should consider any wishes of the child, the desirability of preserving family relationships and informal support networks and who is best placed to represent the child.

Usually, a child's parents have parental responsibility but this can be affected by court orders under the Family Law Act or child protection laws.

A person making decisions on behalf of a child must consider the wishes of the child and act in the best interests of the child. (NDIS Act, sections 74-77 and NDIS (Children) Rules)

Challenge

Dealing with situations where parents are not willing or able to fulfil their obligations under the NDIS legislation or to make participant plan decisions that are consistent with the principles and object of the NDIS Act.

Providing effective support for decision making when children with disability are in care where constraints include a lack of accurate information about the number of children with disability in care, the frequent lack of direct relationship between the guardian and the child and where caseloads in the child protection system impede support for decision making.

Recommendations p 10

Issue 7: NDIA response to market failure in support for decision making

Current practice

Very few providers display an understanding of support for decision making in their practice. This includes providers of core supports whose staff should support decision making in people's day to day lives as well as capacity building organisations that should

work to build the capacity of people with disability to make decisions and of supporters to support decision making.

For some participants, Support Coordination is included as a funded support in their plans. Anecdotal evidence from participants and family members is that this has been very positive (even transformational) in increasing the participants' capacity to make decisions and to be less dependent on long term carers.

There are very few individuals or organisations providing training in support for decision making.

Current supported decision making pilots are testing features of:

- The availability of volunteers
- Training and support requirements
- A risk framework from supporters to substitute decision making

The revised Catalogue of Support has four (4) items that can be used to enable participants to purchase support for decision making for themselves and their supporters. These include:

- Assistance with decision making, daily planning and budgeting (8001)
- Training for parents and carers (15008)
- Assist Life Stages Transition (8004 & 8005)
- Training in planning and Plan management (1509)

Challenges

To develop a market of providers skilled in the provision of support for decision making and in increasing capacity of participants and supporters in support for decision making.

To ensure that support for decision making is provided by a person who has minimal conflict of interest in carrying out the role.

Recommendations p11

Issue 8: Research coordination to build an evidence base for practice

Current practice

The NDIA has a position of Manager Research and has commissioned research in the targeted area of assistive technology but does not currently have a research agenda.

La Trobe University has a robust group undertaking strong research into support for decision making for people with intellectual disability and acquired brain injury including a PHD student looking at decision making support for guardians. The group has published a series of papers on the process of support for decision making and in 2015 secured a four

year ARC linkage grant partnering with Offices of the Public Advocate or the equivalent in Victoria, NSW and Q'ld. This has resulted in engagement that is fairly comprehensive and will be complimented by links currently being established in WA through Assoc Prof Angus Buchanan at Curtin University. The Linkage partners will monitor research into support for decision making across Australia and have recently committed to analyse the evidence from existing and completed pilots.

Melbourne University is undertaking work focused on support for decision making for people with mental health issues.

Whilst practice models of supported decision making exist in the UK, Sweden and Canada, there is little research.

Challenges

Clarifying the role of the NDIA in relation to research.

Operationalizing research in good practice in scalable ways.

Each jurisdiction has different legislation related to decision making and substitute decision making.

Recommendations p11

Recommendations by NDIS systems

This set of recommendations re-orders the recommendations on pages 6 to 10 in relation to responsibilities for different sections of the NDIA.

- A) That the Agency uses the term 'support for decision making' pending finalisation of the National Supported Decision Making Framework.

Service Delivery Operating Model

In relation to the nature of support for decision making, the IDRG recommends that the NDIA:

- B) Develops a set of practice guidelines for support for decision making in the NDIS based on the National Decision Making Principles outlined by the Australian Law Reform Commission.
- C) Strengthens its relationship to researchers to ensure the emerging evidence base strengthens and informs:
- Capacity building in the ILC
 - The work of Support Coordinators
 - Items in the Support Catalogue
 - Decision making support in packages of reasonable and necessary support.

In relation to the allocation of support for decision making, the IDRG recommends that the NDIA:

- D) Adopts a pragmatic approach to support for decision making during surge whereby:
- The concept and practice of support for decision making is emphasized in preplanning workshops and interaction with the LAC.
 - Capacity building training and resources are readily available through the ILCB. This includes skill building opportunities for participants and a range of potential supporters.
 - In areas in which participants transition into the NDIS prior to the roll out of the ILCB, that the NDIA runs or facilitates the running of information and capacity building sessions to enhance support for decision making of people with cognitive impairment.
 - The most vulnerable participants are prioritised to receive funded supports for decision making as part of their first preplanning and plan preparation processes, i.e. prior to the preparation of the first plan.
 - Funded supports to build capacity for decision making (for both the participant and their supporters) are included in the packages of participants with cognitive impairment to ensure that at the second planning conversation, support for decision making follows a more effective and accountable process.
- E) Recognises the most vulnerable participants as those who:

- Live in closed systems such as group supported accommodation
 - Lack effective informal support and have no/few unpaid supports in their lives
 - Are involved in fundamental life changes in their first plan (eg moving out of an institution)
 - Are connected to the criminal justice or child protection systems
 - Have different view to their family / informal supporters
 - Have families whose views are in conflict with principles of NDIS.
- F) Recognises that some participants will require ongoing support for decision making in order to uphold their human rights and meet the requirements of the NDIS Act.
- G) Articulates more clearly the purpose and parameters of the Support Coordination roles including to assist participants to enhance their:
- Capacity to make decisions
 - Self efficacy, self management and empowerment
 - Personal safeguards.

In relation to nominees, the IDRG recommends that the NDIA:

- H) Works toward a best practice approach to the issue of nominees as identified in this paper.
- I) Makes changes to the nominee rules and operational guidelines to ensure that nominees are educated about the primacy of the person's will and preferences and understand how to operationalise their role with respect to the participant's "personal and social well being" in a rights based framework.⁶
- J) Develops guidelines to distinguish the different circumstances giving rise to the use of nominee provisions, Support Coordination and Guardianship.

In relation to children under 18 years, the IDRG recommends that the NDIA:

- K) Develops protocols to guide staff in ensuring there is an appropriate person to represent the child where, despite maximum available support, parents are not making appropriate NDIS planning decisions for their child. That the protocols are developed jointly with the Children with Disability Australia (the peak advocacy body for children) and family leaders.
- L) Ensures that the delegate for decision making for children in care has a first hand relationship with the child.

In relation to research coordination, the IDRG recommends that the NDIA:

- M) Works together with lead researchers in support for decision making to ensure that NDIA practice is informed by and consistent with emerging evidence.

⁶ The framework for support for decision making (Bigby and Douglas, 2015, 15) assists a supporter to identify and describe the decision in ways that retain will and preferences as the primary focus while guiding the supporter to take account of scope, who is involved, consequences, constraints and time frames

- N) Encourages and assists researchers to disseminate their research in forms that are readily accessible to people with cognitive impairment and their families.
- O) Develops and implements a model for disseminating research to enable staff, participants and families to be more competent consumers of research, able to distinguish evidence based resources.

Engagement: the IDRG recommends that the NDIA:

- P) Co-designs and promotes information about support for decision making targeted to the people with disability, families and informal supporters, services and NDIA staff including:
 - Communicating about the use of term ‘Support for decision making’
 - A focus on children and their parents in all NDIA activities aimed at developing support for decision making
 - Ensuring all information for parents of children and young people also includes information about supporting their child to make decisions.
- Q) Ensures that the issue of support for decision making is addressed in preplanning sessions.
- R) Explores with public advocates/guardians, the advocacy sector and funded Support Coordinators what role they may play in providing nominees.

Learning and Culture: the IDRG recommends that the NDIA:

- S) Ensures that Agency and outsourced staff undertaking planning activities can describe, recognise, demonstrate and foster good support for decision making practice for participants.

Information, Linkages and Capacity Building : the IDRG recommends that the NDIA:

- T) Ensures that the ILCB Commissioning Framework includes support for decision making as one of the key deliverables of funded services. This includes skill building opportunities for participants and a range of potential supporters.

Reasonable and Necessary Support: the IDRG recommends that the NDIA:

- U) Provides support for decision making in the plans of participants especially where capacity building in relation to support for decision making is unavailable or likely to be insufficient in the ILCB.

Market and Sector Development: the IDRG recommends that the NDIA:

- V) Develops an item related to support for decision making in the Support Catalogue including:
 - A role description for supporters of decision making

- An outline of the skills, competencies and personal characteristics required for a DM supporter
 - An outline of the core topics for training for supporters of decision making.
- W) Builds requirements in relation to demonstrating support for decision making into the provider registration process.
- X) Undertakes a targeted registration process to encourage user led capacity building organisations to register in the Assist Life Stages Transition cluster to provide training and support for decision making and Support Coordination.

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Victorian Government Supporting Decision Making Guide (which includes resources for people with disability and a guide for disability support workers):
<http://www.dhs.vic.gov.au/about-the-department/documents-and-resources/policies,-guidelines-and-legislation/supporting-decision-making-guide>

WA Individualised Services – <http://waindividualisedservices.org.au/supported-decision-making-project-resources/>

Appendix A Members of working group

This paper was written by Belinda Epstein-Frisch together with a small working group of the Intellectual Disability Working Group composed of:

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In addition, Michelle Browning of the Office of the Public Advocate and PhD student studying supported decision making provided feedback on the paper.