

Independent Advisory Council to the NDIS

What should the NDIA understand about Intellectual Disability?

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**Independent
Advisory
Council**
to the 

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Summary and Recommendations

Recognising that the NDIA understanding about intellectual disability will have a significant influence on the shape of future support, the Intellectual Disability Reference Group (IDRG) developed this advice to outline what is required to ensure that in all its functions, the Agency enhances the opportunities for people with intellectual disability to live ordinary lives included in their community.

The paper identifies:

- Underpinnings at the systemic level necessary to ensure the NDIS architecture supports contemporary practice;
- Principles to guide practice in working with participants;
- Elements of NDIS staff recruitment and training; and
- Outcomes measures to determine the impact of this guidance.

Immediate Priorities

The immediate priorities are identified to reflect the Agency's focus in the lead up to full scheme roll out. Priorities include:

1. To ensure that the ILC is effectively framed to reflect the content of this paper including:
 - a. Ensure that funded resources maximise choice, control, independence and community inclusion and use a developmental approach
 - b. Ensure people with intellectual disability have equitable access to resources
 - c. Build the capacity of people with intellectual disability including but not limited to self advocacy and support for decision making
 - d. Build the capacity of families to support their family member with disability
 - e. Support the community to embrace the participation of people with intellectual disability in all aspects of community life
 - f. Prevent people with intellectual disability from slipping into the need for funded supports, including:
 - i. Take account of the effects of an intellectual disability on each individual's ability to understand NDIS related decisions
 - ii. Take account of the interplay between an intellectual disability and a person's life circumstances that may make the person reluctant to identify with having a disability or to accept support services
 - iii. NDIA decisions are informed by a sound understanding of the interplay of roles between disability support and other service systems including health and justice services and the challenges of obtaining these services.
2. To ensure that the most vulnerable participants receive independent, funded support

with decision making (SDM) as part of pre-planning and preparation for the first plan.

Indicators of vulnerability include participants who

- a. lack effective informal support and have no unpaid supports in their lives
 - b. are involved in fundamental life changes in their first plan (e.g. moving out of an institution or State/Territory supported accommodation is being transferred to the non-government sector. Where changes flow from decisions of a State/Territory jurisdiction, that jurisdiction has a responsibility to contribute to the support for decision making.)
 - c. have differing views from their family / informal supporters
 - d. have families whose views are in conflict with principles of NDIS
 - e. are connected to the criminal justice and child protection systems
3. To ensure staff recruitment processes and practices reflect the intent of this paper (see pp7- 8)
 4. To review the Learning and Development Framework to ensure training and development of new staff reflect the intent of this paper (see p8)
 5. To revise the Outcomes Framework to strengthen the measures of participant planning around risk and safeguards.
 6. To review practice guidance to staff to ensure consistency with the practice principles identified at the participant level. The IDRG recognises that NDIA practice reflects these principles at the highest level but that more work is required to ensure implementation in all situations.
7. These priorities specifically include the agency ensuring that people with intellectual disability have central roles in it including by being employees of the agency, being members of staff selection panels and having a substantial role in training of agency staff.

At one year

- All participants with intellectual disability are offered support with decision making as part of their plan to maximise their contribution to planning at the subsequent plan review.

At full scheme implementation

That processes are put in place to ensure that:

- Participants have the time and support they need to be actively engaged in decision making in all NDIS processes relevant to their personal circumstances
- Support for decision making including training for supporters is an integral part of the plan of all participants with intellectual disability

Attachment A What should the NDIA understand about Disability?

Preamble

The NDIS provides a unique, once in a generation opportunity to enable people with disability, including people with intellectual disability to achieve active citizenship. The NDIA's understanding about intellectual disability will have a significant influence on the enabling people with intellectual disability to achieve active citizenship.

A thorough understanding of the lived experience of a significant group of people with intellectual disability is fundamental to the Agency proceeding in ways that enhance their dignity and respect. The lived experience of most people with intellectual disability continues to be based on low expectations and institutionalised ways of thinking which result in a loss of personhood and citizenship.

Our society values youth, wealth, power, good health, physical prowess and intelligence. Traditionally, measured against these dominant values, people with significant disability, including people with intellectual disability, have been socially devalued. Consequently, people with disability have been perceived as subhuman, a menace, objects of pity, burden of charity, innocent and childlike. The dominant perception and response was that people with disability needed to be protected from society and society needed to be protected from people with disability and this led to a segregated society that congregated people together and isolated them from family, friends and community.¹

At the systemic level

1. The NDIS needs to ensure that NDIA structure, policy and operational practice is based on
 - The social model of disability
 - The UNCRPD
 - Acknowledgement that people with intellectual disability make up approximately 60% of scheme participants
 - Assumption of capacity and potential
 - Co-design.
2. ILC services as well as planning, funding and plan implementation support for each individual:
 - Maximises choice and control, independence and community inclusion
 - Embraces a developmental approach (rather than an approach of care)
 - Uses evidence-based best practice including
 - Person Centred Active Support
 - Quality Positive behaviour support
 - Supported decision making
 - Capacity building
 - Promotes positive risk, providing support and assisting in the development of safeguards to enable a person to experience the dignity of risk including before, behind and beside models for decision making and choice

Has a focus on building the capacity of people with intellectual disability and educating/involving families

- Take account of the effects of an intellectual disability on each individual's ability to understand NDIS related decisions
- Take account of the interplay between an intellectual disability and a person's life circumstances that may make the person reluctant to identify with having a disability or to accept support services
- Are informed by a sound understanding of the interplay of roles between disability support and other service systems including health and justice services and the challenges of obtaining these services.

3. That NDIS systems are aligned to promote:

- A workforce that can communicate effectively with people with intellectual disability
- Skilled staff in Person Centred Active Support, developmental principles, self advocacy and advocacy competencies/guidelines
- Responsive services with strong consumer participation and individualised planning processes
- Staffing processes that promote continuity with people using services to heighten opportunities for the development of trust
- Responsive engagement with people with disability that distinguishes localised system functions from those that must be centralised
- Participants' self-determination and therefore self-directed services

At the participant level, practice should embrace

Principles	Principle into practice	Implications for NDIS
There are high expectations for all people and an assumption that all can participate in the opportunities of an ordinary life	Staff working with participants start from the assumption that people can make real choices	All information is framed positively. Stories include examples of positive risk including safeguards that enabled people to try new things. Stories accurately reflect the time taken to experience success.
	People are given the opportunity to try new things and to change their mind	People are supported to become more independent, to work and be included

<p>Each person with disability is different and is at the centre of discussion</p>	<p>Discussions value a person's rights, responsibilities, cultural and family heritage, aspirations, goals and needs.</p>	<p>Processes are put in place to maximise the involvement of the person with ID. E.g.</p> <ul style="list-style-type: none"> • Information and resources are provided in formats that most participants can understand • Extra lead-in time for planning process to allow goal clarification and explore role of community and/or informal supports • Longer planning meetings to allow
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Principles	Principle into practice	Implications for NDIS
		<ul style="list-style-type: none"> • Work in ways that clearly distinguish the voice of the person from the voice of the family • Identify opportunities for improvement and encouraging growth • Develop processes to receive feedback about how things could have been done differently in a planning conversation • Develop collegiate planning teams that specialise in particular target groups • Capacity Building/Advocacy Support/Rights training/ Self Advocacy training is available to support maximum participation of the person • Support with plan implementation and monitoring of quality and outcomes of supports
	<p>Communication is 'individualised', using whatever approach will assist the person to hear, understand and provide their views</p>	<p>Staff have a mindset to be open to different ways of communicating</p> <p>Staff are trained and skilled to communicate with people with ID</p> <p>Participants' communication partners are welcome to attend meetings</p> <p>Variety of communication methods and approaches are possible</p>
	<p>Discussion takes place in a rights based framework</p>	<p>Participants are supported to understand their rights and responsibilities.</p>

<p>People are supported to make decisions</p>	<p>People have all the information they need to make a decision</p>	<p>Information is provided in a variety of</p> <ul style="list-style-type: none"> • Formats • Media including one to one conversations • Locations <p>Information is provided in a timely manner</p> <p>Participants have the opportunity to consider and discuss the information, consider their decisions and make their decisions with support of an independent person</p>
	<p>People have the opportunity to see that</p>	<p>People are given support to try new things, to hear stories of people like themselves who</p>

Principles	Principle into practice	Implications for NDIS
	different	different experiences
		Families, carers and allies are recognised as planning partners to support the goals as well as to meet the needs of their family member.
	People have the time required to think and to make decisions	Time frames are flexible and discussion on multiple occasions is allowed and encouraged
	People have support to maximise their decision making and, where necessary, have a nominee to make decisions	People are assisted to enhance their skills to enable them to make decisions for themselves – self advocacy training is available
		People have opportunities to make decisions
Families and allies are supported to enhance the voice of the person and recognise it as different from their own Trained supporters are available to support people with decision making.		
	There is clear accessible information about the roles and responsibilities of NDIS nominees and circumstances of their appointment The agency appoints a nominee wherever substitute/fully supported decision making is in fact required. Nominees are trained to fulfil their responsibilities	
People are offered support in their engagement with the NDIS	People are best supported by consistent people with whom they have a relationship and whom they trust	Full scheme design post roll out recognises the importance of consistent NDIS contacts over time Time is taken to build a relationship of trust with each individual. Ensuring that the person has access to support from a consistent source to enhance likelihood of the development of a trusting relationship

No one is left unsupported	Advocacy support for decision making is available for all participants including those who lack informal support or where people around the person prevents their voice being heard
People are assisted to	People are assisted to speak up about their

Principles	Principle into practice	Implications for NDIS
	provide meaningful information about their needs	needs Participants are encouraged to contribute information from people and services that have supported them well, particularly in relation to support for decision making NDIS staff have skills to make judgements about information that is important to facilitate quality decisions and seek out that information
	People are supported when others are making decisions that are not in accordance with the objects and principles of the NDIS Act	NDIS has safeguards that protect the rights of participants particularly those with an intellectual disability.
		Training is provided to participants and informal supports to ensure they understand the Principles of the NDIS Act and UNCRPD
	People are supported to implement their plan	People receive assistance of a nature and duration that they need
People understand their position as service users and co-designers with rights as opposed to being dependent clients		Participants are supported to understand the shift in power that comes from individualised funding, to see themselves as co-producers of their own supports and the ability to be supported in the manner of their choosing and to change provider
People learn to have more choice and control in their lives and in their support		Capacity building is provided including in support for decision making, enhancing self efficacy and continuing to learn about choice and control.

NDIA Staff Recruitment

Fundamental requirements include importance of

- Employing people with intellectual disability in the NDIS. This provides positive opportunities for employees with ID and assists colleagues to

gain valuable insights by working with people of varying abilities. In addition to functional roles, people with intellectual disability would offer valuable skills in accessible communication and as peer educators. The use of a target for recruitment is encouraged

- Having people with intellectual disability on selection panels
- Having minimum requirements in relation to working with people with intellectual disability
- Ensuring staff with a range of expertise in intellectual disability who can support other staff as required, including expertise in complex behaviour support and the interplay of roles between disability support and health and justice services.

Training of staff

Staff training should include

- Theoretical underpinnings of social model of disability and supporting people in the context of the UNCRPD and their fundamental human rights
- NDIA Values-based induction and training
- Person Centred Planning
- Support for Decision Making
- Legislation, Guardianship, Administration, Nominee provisions
- Enabling risk and

developing safeguards Staff

training should ensure staff:

- Reorient from previous understandings including from
 - A capped crisis driven to reasonable and necessary support across the lifespan
 - Welfare provision to an insurance approach
 - A medical model of disability to a social model of disability
- Become comfortable with communicating with people with intellectual disability and those who use different means of communication
- Recognise and value the diverse ways of building trusting relationships including with people who may initially be suspicious of the NDIA
- Identify and recommend evidence based practices e.g. 'Individualised approaches that support self-determination
- Demonstrate a capacity to assist people with intellectual disability to

- develop safeguards and engage in positive risk
- Support individuals to have maximum control in decisions but also recognise the need for fully supported/substitute decisions where necessary
- Recognise a participant's ability to provide necessary information and support them to obtain added information where necessary
- Demonstrate a commitment to assist all participants to have ordinary lives included in the community
- Recognise existing service providers as valuable sources of knowledge about an individual while also taking account of conflicts of interest
- Have competencies in
 - Sorting through complexities of parent vs person with disability goals oldentifying opportunities for improvement and encouraging growth
 - Dealing with conflict
 - Managing planning and meeting processes

Aspects of staff training must be provided by and with people with intellectual disability involved in staff training

Measuring Outcomes

Measuring Outcomes

- Individual
 - Participants identify risks and develop safeguards
 - Participants have increased engagement in decision making
 - Participants have more choice and control
 - Participants have lives that are typical for people of their age and heritage
- NDIS
 - PWID employed by the agency
 - PWID on selection panels
 - PWID engaged in training staff
 - Staff appraisal takes into account principles and practice elements of this advice
 - Staff on participant pathways are competent at implementing principles and practice elements of this advice

- Continuity of relationships between NDIA staff and participants
 - NDIS materials and resources are available in easy read and accessible formats
 - Impact
 - Participants report that NDIA staff assisted them to have the lives they wanted
- Methods for data collection include:
- Seeking feedback from people with intellectual disability and allies in relation to NDIA performance against the NDIA Service Charter
 - Data collected through the Outcomes Framework
 - Quality of Life indicators and measures
 - An audit of sample of plans including seeking feedback from the participants and allies
 - Audit of NDIA materials and resources to identify readability and accessibility of information
- NDIS information resources in multiple formats