



## **Looking Back, Looking Forward**

*fulfilling the promise of the NDIS for people with intellectual disability*

Version 1.0

Date: 30 June 2013

National Council on Intellectual Disability (NCID) has over 5,000 members representing all 8 states and territories. In addition to having people with intellectual disability on our Board, NCID receives policy advice from Our Voice. Our Voice is a committee of NCID's Board, the membership of which is exclusively people with intellectual disability representing all states and territories.

NCID is the recognised national peak body with the single focus on intellectual disability, ie, our actions and priorities centre on issues that affect the lives of people with intellectual disability and their families.

NCID's mission is *to work to make the Australian community one in which people with intellectual disability are involved and accepted as equal participating members.* We do this by:

- listening to people with intellectual disability and their families
- promoting and upholding the UN Convention on the Rights of Persons with Disabilities
- developing and promoting creative policies and practices
- speaking to politicians, public servants, business and community leaders about the lives of people with intellectual disability and their right to have equality of opportunity

National Council on Intellectual Disability is a social profit organisation. NCID was created in 1971 by parents and friends in an endeavour to improve the quality of life of people with intellectual disability and to fill the need for national unity and information.

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## Statement of Principles

- ☼ All people have inherent dignity and worth and equal and inalienable rights.
- ☼ All people are valued members of the Australian Community.
- ☼ People with intellectual disability as equal participating members of the Australian Community have the same rights:
  - ☼ to respect for their individual autonomy and independence
  - ☼ to make their own choices
  - ☼ to participate in decisions which affect their lives
  - ☼ to pursue any grievance which affects their lives
  - ☼ to diversity of choice for housing, education, work, recreation and leisure
  - ☼ to equity and justice
  - ☼ to be empowered to take their full place in the Australian Community
  - ☼ to dignity and privacy in all aspects of their lives

### **National Council on Intellectual Disability will:**

- ✓ work to make the Australian Community one in which people with intellectual disability have full and equal enjoyment of all human rights and fundamental freedoms and are involved and accepted as equal participating members.
- ✓ promote and protect the human rights of all persons with intellectual disability, including those who require more intensive support.

### **Consultation Statement**

National Council on Intellectual Disability consults people with intellectual disability and family members through our State and Territory Agency Members. In particular we:

- ➔ conduct an annual survey of members and stakeholders
- ➔ hold two meetings a year, rotating through all States and Territories
- ➔ present at the Having a Say Conference each year, attended by over a 1,000 delegates the majority of whom have a disability
- ➔ hold forums on specific issues
- ➔ sponsor actions and representations on issues of importance to people with disability

On the issue of National Disability Insurance Scheme National Council on Intellectual Disability has consulted extensively with our members, people with intellectual disability and family members.

The National Disability Insurance Scheme (NDIS) has been the focus of NCID's work for the last 12 months and will continue to be so for the next 3 years.

NDIS activity undertaken by NCID in 2012 - 2013:

- made submissions to Productivity Commission Draft and Final Reports
- made submission on NDIS Draft Bill
- made submission on NDIS Draft Rules
- made submission on COAG consultation
- consulted with members, including people with intellectual disability through Our Voice
- developed NDIS Fact Sheets

- held forums in
  - Adelaide
  - Melbourne x2
  - Sydney
  - Launceston
- supported Alliance forums
- participated in AFDO discussions

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*This publication has been prepared by the National Council on Intellectual Disability Inc. for the Australian Government, represented by the Department of Social Services. The views expressed in this publication are those of the National Council on Intellectual Disability Inc. and do not necessarily represent the views of the Australian Government.*

*I like living in my own house. I live with my boyfriend and we get help from my parents and our friends and others but we can do what we like. I like going to work and to my church and to the football. Best of all I can cook for Tom and our friends, with some help from mum and my workers ...*

Anna-marie, (32), person with intellectual disability

*It was a shock, I did not know how many people knew her. When she got sick, really very ill, people from the supermarket she works in, her friends, her neighbours, people from her church visited her in hospital and at home, they cooked meals, cleaned her house, did her shopping and made sure she had enough videos. It was amazing! She is part of her, or should I say, our community. I guess she has only got what she has given to others over the years.*

Amanda (age not disclosed), a very proud mum

## Preamble

This paper highlights the key issues that were identified by people with intellectual disability and their families through the extensive consultations that NCID and our Agency Members conducted throughout 2012/2013 on the National Disability Insurance Scheme (NDIS).

The issues in this paper act as a guide as we now consider the implementation of the NDIS and its ongoing development to meet the aspirations of all people with intellectual disability to live a life of full social and economic participation in the life of their communities.

## Introduction

The NDIS is not merely a funding scheme providing support to people with disability, the NDIS must have a clear purpose and must deliver clear outcomes for people with disability. It must be an enabler.

The danger is an historical one: see a problem - throw money at it. It is unclear whether governments see people with disability as the problem, service providers as the problem or elements in the community (for example, employers) as the problem.

The language of the Bill and rhetoric associated with it sees the solution to the problem (whatever it is) as giving people (some) money and giving them (some) choice so that they can receive (some) support. Why? What real outcomes should people with intellectual disability expect from their involvement in the NDIS?

The answer lies with the **National Disability Strategy** which seeks to positively change the position of people with intellectual disability in Australian society.

The shared vision is for **an inclusive Australian society that enables people with disability to fulfill their potential as (equal) citizens.**

National Disability Strategy, p 8

The **National Disability Strategy** and the changes it demands of all participants in our society demonstrates that money, choice and support will not produce citizenship for people with disability.

The NDIS is the important element of the **National Disability Strategy** as it enables people with disability to participate in the building of an 'inclusive Australian society', not merely to participate in a society owned and controlled by others.

It is interesting that the vision sees people with disability being enabled to ‘fulfill their potential as **equal** citizens’; citizenship is not divisible, and yet the **National Disability Strategy** sees people with disability as currently being unequal, lesser citizens. Citizenship is something that is given, it confers rights and responsibilities; it would be more accurate to say that people with disability have unequal participation in their citizenship.

If we take the **National Disability Strategy** as the key document and the NDIS as the enabler for people with disability to exercise their rights and responsibilities, the success or otherwise of the NDIS must be measured against the outcomes of the six areas of the **National Disability Strategy**. In five years time, how will the NDIS have enabled people with intellectual disability, through exercising their rights and responsibilities, to shape Australian society to become, inclusive, accessible, equal, just, economically secure, educated and healthy?

The NDIS from this point of view. It is not enough to say, does the NDIS provide more money, does the NDIS give people more choice, does the Bill give people more support. The question is, will the NDIS enable people with disability equal participation in their rights and responsibilities of their citizenship? Or, will it be more of the same?

### Key Issues for people with intellectual disability

1. Inclusion of all people with intellectual disability, including those with higher IQ scores
2. Respect for who people with intellectual disability are and their achievements
3. People with intellectual disability have control over their lives, not necessarily over ‘support’ funding
4. Self advocacy is important for people with intellectual disability and must be supported, including with resources
5. All service providers, both generic and specific, use evidence based practice (leading [best] practice)

*See quotes at the end of this paper, the voices of people with intellectual disability*

## National Disability Strategy

The National Disability Strategy covers the six principle areas of life for all Australian citizens and sets out an outcome for each area. Each outcome starts with “people with disability ...”, but each outcome applies to all Australians. These are not outcomes only for people with disability, but also for their neighbours, their work mates, their friends and family. They are outcomes for all Australian citizens and they should be read as such. And, by working to achieve these outcomes, people with intellectual disability will be benefiting all members of their community not just themselves.

As we read each of the six areas, the challenge is to image how the NDIS will enable people with intellectual disability to be participants in achieving the outcome; not being done ‘for’ or ‘to’ them but being active citizens in making the outcomes the reality for all Australians.

### 1. Inclusive and accessible communities

People with disability live in accessible and well-designed communities with opportunity for full inclusion in social, economic, sporting and cultural life.

## 2. Rights protection, justice and legislation

People with disability have their rights promoted, upheld and protected.

## 3. Economic Security

People with disability and their families have economic security, enabling them to plan for the future and exercise control over their lives.

## 4. Personal and community support

People with disability and their families have access to a range of supports to assist them to live independently and actively in their communities.

## 5. Learning and skills

People with disability achieve their full potential through their participation in an inclusive high-quality education system that is responsive to their needs. People with disability have opportunities to continue learning throughout their lives.

## 6. Health and wellbeing

People with disability attain their highest health and wellbeing outcomes throughout their lives.

### **The success of the NDIS will be judged by these Outcomes:**

- ✓ Have all people with intellectual disability been engaged with their community in achieving these Outcomes?
- ✓ How have people with intellectual disability funded by the NDIS been actively engaged (enabled) with their community in achieving these Outcomes?
- ✓ How many people with intellectual disability, including those with higher IQ scores, have not received NDIS and been engaged with their community in achieving these Outcomes? How many have not been engaged?
- ✓ In what ways has the funding of the Agency built the capacity of people with intellectual disability to be actively engaged with their community in achieving these Outcomes?
- ✓ How has the Agency engaged with the community to achieve these Outcomes?

The success of the NDIS is not a question of numbers, how many dollars provided, how many people funded, how many support hours. The success of the NDIS can only be judged by a real change in the lives of all people with intellectual disability a change where we can all proudly state:

**In Australian society, all people with disability fulfill their potential as citizens.**

## Intellectual Disability

**All people with intellectual disability, including those with higher IQ scores (70 - 85) must be specifically included in the National Disability Insurance Scheme.**

### Intellectual disability is ...

... a lifelong disability that can affect many different areas of a person's life. Many factors can cause intellectual disability; however, in many cases, no identifiable cause is found. Some people with intellectual disability may also have other disabilities or conditions such as physical disability, psychosocial disability or a speech impairment.

A person with intellectual disability is able to learn. With appropriate support and training within a culture which values the inclusion and contribution of each individual, people with intellectual disability can develop the skills and confidence to enable them to actively participate as equal members of the community.

### Defining intellectual disability

Intellectual disability is characterised by significant limitations, which originate before age 18, in:

- ▶ intellectual functioning; and
- ▶ adaptive behaviour expressed in conceptual, social and practical skills.

### Intellectual functioning

Intelligence is a general mental ability. It includes reasoning, planning, solving problems, thinking abstractly, comprehending complex ideas, learning quickly, and learning from experience. Intelligence reflects a capacity for understanding our surroundings - catching on, making sense of things, or figuring out what to do.

### What the Productivity Commission said ...

▶ *The criteria for eligibility do not separately identify people with intellectual disabilities. They are grouped with other people with 'significantly reduced functioning in self-management'. **There is full coverage of intellectual disability.*** p 78.

▶ In addition to the above requirements, people would have to meet at least one of the following conditions. They would:

have significantly reduced functioning in self-care, communication, mobility or self-management and require significant ongoing support. For example, this would include people who need support in toileting, who require significant support for mobility and/or communication or **who require supports in self-management and planning to live successfully in the community (such as those with intellectual disabilities** or those with significant and enduring psychiatric disabilities). p 30.

▶ While the above categories (severe and profound core activity limitation) can be useful, as can the broader International Classification of Functioning, the appropriate definition of disability should take account of the policy context in which government is applying it and of the practical ease of identifying disability. For example, under the ABS's approach, many intellectual disabilities might not be categorised as severe or profound (reflecting the omission of learning as a 'core activity limitation'). **However, in the Commission's view (chapter 3), there are strong grounds for a disability scheme to provide funded supports to people with an intellectual disability.** p 111

▶ A person receiving funded support from the NDIS would have a disability that is, or is likely to be, permanent. The definition of 'permanence' would **include people with long-term functional**

**limitations who may only need episodic support.** In addition, people would have to meet at least one of the following conditions. They would:

– have significantly reduced functioning in self-care, communication, mobility or self-management and require significant ongoing support (3a). For example, this would include people who need support in toileting, who require significant support for mobility and/or communication **or who require supports in self-management and planning to live successfully in the community** (such as those with significant and enduring psychiatric disabilities or **those with intellectual disabilities**) p 157.

▶ Around 40 per cent of **individuals with intellectual disability** with life-long care and support needs do not face a core-activity limitation (AIHW 2008a). Even so, their actual **capacity to participate in society may be lower than those identified as having such limitations.**

As noted by the AIHW:

**“People with intellectual disability encounter special challenges that are different from people with other types of disabilities in a number of important aspects.** For example, they have difficulty learning and applying knowledge and in decision making. They may have difficulty identifying and choosing options at key life transition points. They often have difficulty adjusting to changed circumstances and unfamiliar environments and therefore need high support during times of change.

Need for help with core activities may not fully reflect the level of support that an individual with intellectual disability requires to participate in society. Even though they may function relatively well in the familiar routines of self-care and domestic life, and be independently mobile ... **It is therefore important to also consider the level of support that is needed** in non-core activity areas, especially **making friendships, maintaining relationships and interacting with others.** (2008a, pp. 1–2)” p. 171 - 172

▶ A short upfront assessment module would establish whether an individual would benefit from funded support. In many cases, this stage would be waived for:

individuals who unambiguously experience significant limitations in mobility, self care, communication or **self-management**, such as those with quadriplegia, or diagnosed **as having intellectual disability** p. 177.

## All people with intellectual disability are eligible for NDIS funding!

The Productivity Commission's final report into the long term care and support of Australians with disability, which the Prime Minister released in August 2011, judged the disability service system to be unfair, underfunded and fragmented. The main recommendations of the Productivity Commission were that:

- ▶ A National Disability Insurance Scheme should be created to provide all Australians with insurance for the costs of support if they or a family member acquire a disability
- ▶ A National Injury Insurance Scheme should be created to provide no fault insurance for anyone who suffers a catastrophic injury.

### Eligibility

Australia is a signatory to the United Nation Convention of the Rights of People with Disabilities (2006) and has an obligation and responsibility to uphold and promote the principles, articles and purpose of this binding agreement. The Convention clearly states that:

- ▶ *Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.*

**All people with intellectual disability are eligible for NDIS funding, the level of which will be determined by their individual participation needs.**

### Assessment

Assessment raises considerations about not only the processes and tools of assessment, but a more fundamental question about the purpose and direction of that assessment.

Why assess? Is it merely to determine the nature and level of impairment with a negative connotation of what the individual cannot do? Or, is it to identify the nature and level of support and opportunity required to enable a person with intellectual disability to fulfil their potential, to live lives which they and the community value? NCID believes that it is about citizenship for people with intellectual disability, it is about real lives - people with intellectual disability 'leading lives that they have reason to value'.

True participation in community life has implications for assessment that go beyond placing the focus solely on the person with intellectual disability. The environment: physical, social and attitudinal, also plays a part, and in many instances is a major factor, in a person's disability, i.e. disability is an interaction between a person with an impairment and their environment(s).

People with intellectual disability represent one of the most disadvantaged groups in society with poorer education, employment and housing outcomes than any other disability group.

**This was understood by the Productivity Commission when it stated that all people with intellectual disability should be eligible for an NDIS assessment.** This is not to say that they will all receive funding, but that there is sufficient evidence that their disability (the interaction between their impairment and their environments) will likely mean that they will require assistance to participate in their community. This has implications for effective referral to 'mainstream' support and opportunities to participate in and contribute to the community at large in a meaningful way.

### Not another assessment?

Assessments cost time and money and so should only be conducted when necessary. People with intellectual disability will always have an intellectual disability, ie, they will always need support to learn and to participate in their community. In terms of eligibility for NDIS support there is no need for people with intellectual disability to be assessed, they already have been by paediatrician, school counsellors, etc. If for some reason a person has not had an assessment then the appropriate assessments to determine intellectual disability and hence eligible for NDIS funding are those used to determine eligibility for the Disability Support Pension (DSP) (age appropriate versions).

### What the Productivity Commission said ...

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▶ A person receiving funded support from the NDIS would have a disability that is, or is likely to be, permanent. The definition of 'permanence' would **include people with long-term functional limitations who may only need episodic support.** In addition, people would have to meet at least one of the following conditions. They would:

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As noted by the AIHW:

**"People with intellectual disability encounter special challenges that are different from people with other types of disabilities in a number of important aspects.** For example, they have difficulty learning and applying knowledge and in decision making. They may have difficulty identifying and choosing options at key life transition points. They often have difficulty adjusting to changed circumstances and unfamiliar environments and therefore need high support during times of change.

Need for help with core activities may not fully reflect the level of support that an individual with intellectual disability requires to participate in society. Even though they may function relatively well in the familiar routines of self-care and domestic life, and be independently mobile ... **It is therefore important to also consider the level of support that is needed** in non-core activity areas, especially **making friendships, maintaining relationships and interacting with others.** (2008a, pp. 1–2)" p. 171 - 172

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individuals who unambiguously experience significant limitations in mobility, self care, communication or **self-management**, such as those with quadriplegia, or diagnosed **as having intellectual disability** p. 177.

## Person Centred and Flexible or the same old bureaucratic system?

The NDIS discussion paper on Reasonable and Necessary Supports gave 6 guiding descriptions of how reasonable and necessary supports can be judged:

Reasonable and necessary supports:

1. are designed to support the individual to achieve their goals and maximise their independence;
2. support the individual's capacity to undertake activities of daily living to enable them to participate in the community and/or employment;
3. are effective, and evidence informed;
4. are value for money;
5. reflect community expectations, including what is realistic to expect from the individual, families and carers; and
6. are best provided through an NDIS and are not more appropriately provided through other systems of service delivery and support, including services that are offered by mainstream agencies as a part of its universal service obligation to all citizens.

### Where is the person? Where is the change?

In this discussion it is important to remember that a person's disability is an interaction between a person's impairment and their environment. Their environment includes the built environment, services, products, attitudes, schools, medical services, etc. **People are disabled not by their impairment but by society.**

Viewed this way the question of 'reasonable and necessary' support becomes one of human rights and not limiting expenditure (see points 4 & 6).

To ensure that all Australian citizens (and residents) have equal access to their community and its resources funding support must be given on an equal basis regardless of the cost. The only relevant guiding descriptions are 1 & 2. **It is important to note though, that the concept of self management referred to by the Productivity Commission is missing from guiding description no 2 and must be reinstated if the NDIS is to meet its aims.**

NCID is very concerned by expressions in the NDIS discussion paper which appear to qualify the funding support that a person with intellectual disability will be entitled to.

The following expressions cause concern:

... *consistent decision making*; what does this mean when the NDIS is supposed to be person centred and flexible? Will a person be told that the support they need to 'achieve their goals' will not be funded because no one else is funded for that support? If it does not mean this then what does it mean?

... *impact of a person's disability on their participation in the community or employment*; this places the 'fault' solely with the person with disability and not the environment. One of the issues of why people need support is that the community does not meet its obligations to include all people within the community and hence it is a question of human rights not 'deficits'. This means that it is a question of equity with the general community not merely addressing a person's disability.

Example 1: it is not a matter of merely providing a person with a wheelchair, if public transport is not accessible and affordable then it will also mean purchasing a vehicle.

... *'reasonable' taking into consideration factors such as cost effectiveness, value for money of the support, efficacy of the support and relevant community standards (including community expectations about what is reasonable to ask from carers and families)*; again if we are talking about a person centred scheme and one that is flexible then how do you consider cost effectiveness, value for money, and efficacy without ending up with what we have, a support system that tells people with disability what is good for them; also what does the community expect of families! A better question

may be what do people with disability expect of the community? And, is it reasonable to be compensated for the failure of the community to live up to these expectations?

Example 2: a person with intellectual disability (who has a higher IQ score) may have a network of informal support such that they do not need daily funded support. But if they need support to go to the Dr, are made homeless or get into trouble with the police then they will need funded support and this support will probably need to be ongoing. How will they know about the NDIS, how will the NDIS know about them and most importantly how quickly will the NDIS respond to their needs?

... *include early intervention services where there is evidence that the intervention will improve their outcomes*; the interpretation of this statement has major implications for people who have multiple disabilities who need intensive therapy to keep alive.

The contentious point will be guiding description no 3! NCID supports the concept of 'effective' if it means a person achieving their goals and being independent; and if it means supporting a person to participate in their community and employment. As long as effective does not come to mean efficient!

Funding to support people with intellectual disability to participate in their community must be on the same basis as all other government funding. Do we fund health services and education that are not evidence based? It is reasonable to expect the government funding provided through the NDIS to actually support people with intellectual disability to maximise their independence and to support their participation in the community. This requires the NDIS to promote evidence based supports and to ensure it engages with the community as to what the evidence tells us. This has not been government practice to date.

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## Choice and Control by People with Disability

The National Disability Insurance Scheme Bill stated:

4 (14) Innovation, quality, continuous improvement, **contemporary best practice and effectiveness in the provision of supports** to people with disability are to be promoted.

Historically people with disability have had little control over their lives as service providers and bureaucrats made decisions for them because 'they know best', because people with disability can not be trusted to make 'informed decisions' (ie, the decision that others would make) and that people with disability have to be 'risk managed'. The NDIS marks a change from this outdated attitude towards people with disability. NDIS Principles invoking the UN Convention on the Rights of Persons with Disabilities are clear that the UNCRPD Principle and right of self-determination is to be exercised through choice and control.

If anyone with a disability is deemed not to have the capacity to exercise choice and control then a formal transparent process which has independent review must be utilised. The assumption must be that people with disability have the capacity to make decisions, support must be provided and any restrictions must be specific and independently reviewable.

People with disability will not be alone in a 'sea of sharks'. It is important to acknowledge that there are many safeguards which do not discriminate against people with disability. There are many 'generic regulations and licencing arrangements' as well as consumer protection laws which will protect people with disability as much as they protect all members of the community. Specific 'disability' regulation necessary is discriminatory by its very nature, ie, controls and restrictions are going to be placed on people with disability because they have a disability! This would be a clear violation of the UN Convention.

And, the NDIS will require:

- ✓ the active involvement of the NDIS Agency, the development of plans, the provision for the appointment of nominees, etc.
- ✓ the adequate funding of independent advocacy
- ✓ people with disability being in and of their community
- ✓ the adequate funding of information and information networks
- ✓ the funding of peer support networks, for people with disability and their families
- ✓ capacity building for organisations and individuals
- ✓ all parties to acknowledge that innovation and creativity is driven by people with disability and families and allies

All these provide safeguards for people with disability as they make decisions about their lives. Yes, people with disability will take risks, they will make decisions that others will disagree with, they will make decisions that do not work out, yes, they will regret some of their decisions, but don't we all? The days of protecting people with disability because they are 'other' have long gone and policy must catch up.

The case for government (non)intervention in a market for disability support is supported by research evidence:

People with disability have an equal right to participate fully in society and to direct their own lives and, unless proved otherwise, have the capacity to act in their own best interests. **Internationally and in Australia, research has shown that reforms to disability**

**and human services which embed greater choice and control for service users have been found to result in better life outcomes for people with disability, as well as more efficient and effective service outcomes** (KPMG for NSW Ageing Disability and Home Care, Draft Policy framework for Choice and Control in the National Disability Insurance Scheme, 24 July 2012, page 9).

‘Nevertheless’ and ‘however’ despite the research ‘showing greater choice and control’ - one of the main aims of the NDIS - and ‘more efficient and effective service outcomes’ and that ‘people have a right to direct their own lives’ there has been a tendency in NDIS discussions to revert to the historical paternalistic position in relation to people with disability where people with disability may be at risk and hence need the intervention of benevolent bureaucrats and service providers.

Either Australians with disability are citizens or they are not! Either Australians with disability have a right to direct their own lives (including taking risks and making mistakes) or they do not! Either Australia will honour its signature of the UN Convention on the Rights of Persons with Disability or not!

**It is time to stop having ‘rights’ rhetoric and restrictive policies. The NDIS must be a real break with the past, the citizenship rights of people with disability must be affirmed in all policy and its implementation.**

### Question of Neglect and Abuse

The issues of neglect and abuse of people with disability are separate from the issue of regulation and must not be used to impose restrictions on people with disability.

Yes, some people with disability suffer neglect and abuse, they do so today and we as a community must stop the abuse. But, children, older people, middle class people, people on benefits, etc, etc, all suffer abuse and we must stop this abuse as well. Abuse is not a disability specific ‘problem’ and nor should it be seen as such and used to curtail the rights of all people with disability.

Anyone who believes that regulations such as disability quality assurance schemes, disability standards, etc, stop the abuse of people with disability should read the Shut Out Report. Anyone who thinks that better quality assurance schemes or better standards will stop the neglect and abuse of people with disability should read the Shut Out report.

Disability quality assurance schemes and disability standards will only limit the choices that people with disability have and enshrine a culture of mediocrity amongst a group of privileged providers who will not have to do anything except get the all important QA tick every couple of years.

It is simplistic and very convenient for governments to impose these of people with disability and then to say we have addressed the ‘problem’. Decades of media reports, ombudsman’s reports and reports from other statutory reports show that they have not.

Governments and regulators must face the hard decisions and act on the causes of neglect and abuse and the known protectors. For example, it is well documented that people with disability who are congregated in segregated services are more likely to suffer abuse; and yet governments continue to fund services that congregate people with disability in segregated settings.

## The voices of people with intellectual disability

*Throughout our many consultations people with intellectual disability expressed clear views on their expectations of and their concerns with the NDIS. Their main issues are listed below, in their own voice:*

### 1. Eligibility

- What happens if someone lives in a group home, does this mean they will no longer be able to live in their home. Will they still get support?
- It should be about choice. Some people are old at 65, some are still young.
- Eligibility needs to be explained better. People who are on the fringes could get lost in the system.
- People don't like assessments, they make people feel bad. People should not have to get assessed again to become eligible.
- Who will help people?
- There is nothing about right to a review of the decision if you don't agree.

### 2. Planning

- Plans need to be accessible – not just in easy English, but DVD, poem, story, whatever is accessible for the individual.
- The legislation says a plan must be started within 14 days of being assessed as eligible. Who will help people? People will need extra help and time to plan. Its hard to see what will happen in the future and people should not be rushed to do their plan quickly.
- There needs to be more flexibility in the planning process. People need to know and trust the person that is helping with their planning. People want an advocate or someone they can trust, someone they nominate and give consent to be there.
- The person who's plan it is needs to be 100% involved, it has to be all about them.
- What if a person has a Guardian, does this mean that person will make all the decisions about the persons plan? It should not be this way. Just because a person needs a Guardian for one part of their life, doesn't mean they can't make decisions about what they want for themselves.
- People need to learn how to plan, many people have not made their own decisions before.
- Review of the plan – the committee felt the legislation took away their control, and wasn't in line with what the NDIS was supposed to achieve, giving them more control. People's circumstances change and they should be able to reflect that in their plan. People should be able to ask for a review of their plan and get one.
- Privacy within the legislation – committee was concerned that people can obtain their information too freely. Are people going to be informed about what information is being accessed and who it is going to and for what reason.
- Nominee – who can that be? Not service provider. Legislation says the CEO needs to approve of your nominee. This could take away peoples control. Should be able to appeal this if it happens.

### 3. Support and Services

- They need to respect privacy and know when to back off. How easy is it going to be to become a service provider. People want the flexibility to employ who they want. It should not only be 'service providers' if people choose.
- Service providers should not be in control.

### 4. Funding

- If you are capable you should be able to manage your funding. Service providers should not hold your funding. There needs to be a financial intermediary.
- Concerns were discussed about how do people prove for eligibility that they have an intellectual disability and at the same time prove they are competent to manage their own funding.

## 5. Review

- Is their set times for review?
- Person/family or significant other should be able to request a review.

## 6. Advocacy/Self Advocacy

- There is not enough focus on self advocacy. People need to be involved more, have more of a say. People need to understand it before they can meaningfully have a say.
- Nominee is not independent because it has to be agree by CEO.
  - What if CEO decides your preference for a nominee is not agreed by CEO?
  - People might not want their legal guardian as their nominee.
  - At what point can you do it on your own, at what point do you need a nominee?
- Advocacy is important because they are on our side, they need to be involved in appeals and reviews and to make sure we get listened to.
- People need to practice and learn about self advocacy.

## 7. Information

- There needs to be a lot more information.
- A lot more information in Easy English and other easy formats like DVD's, personal stories that people can relate to.
- Information needs to be released in Easy English at the same time all other information is released. The timeframe is too short for consultations by the time the Easy English versions are released.

## 8. Communication

- There are online forums, but how can people with intellectual disability give feedback when they are not able to use technology.
- People who run forums aren't equipped to consult with people with intellectual disability.
- The rules of the NDIS need to be communicated clearly and well before it starts so people can have a say about them.

## 9. Other issues

- Reasonable and Necessary – Who will decide what is reasonable and necessary?
- The legislation says NDIS funding won't be given to cover things that are covered by generic services. But there needs to be flexibility. Now at times services provide support for people admitted to hospital, will this still be possible, some people need support from people they know.
- People who live in rural and remote areas can be isolated and transport expensive. How can people have a plan if they cannot afford the transport costs to implement it. Transport that is related to their plan should be covered.
- Some people only need a small amount of support occasionally. For example 2 hours every 3 months to support them to a specialist appointment to interpret information. They should get a small amount of funding that they keep until it is needed, if they don't use it within a certain time it could be rolled over or topped up if necessary.

- One size does not fit all, how can they determine what is reasonable and necessary when people's circumstances vary.
- How will the NDIS fit with what is already happening in states? People who have good packages now shouldn't lose funding or supports under the NDIS.,
- Decision making – "We all want to make our own decisions."

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***I get help with the things that I find hard. It is different than before, I get to choose the people who help me with my money, my holidays and making sure I get to work. They also help me do new things ...***

Anna-marie

***Anna is part of a pilot run by the State government. We spend a lot of time having cups of tea with people she has known for awhile, talking about what she does, what her friends do, what we do. She lets us know if she wants things to change and if she wants to try new things. All this will change for a while as she has told us all that she and Tom are getting married. I do wonder how many cups of tea it takes to organise a wedding?***

Amanda