

Queensland Roundtable on Intellectual Disability

*Breaking Ground:*  
*The NDIS and Intellectual Disability*  
Feedback and Recommendations

July 2012



## Foreword: The Queensland Roundtable on Intellectual Disability

### *History of the Queensland Roundtable*

Community Living Association (CLA) and the WWILD-SVP Association Inc. established the initial Working Group of the Queensland Roundtable on Emerging Issues for People with Intellectual Disability. These organisations originally came together out of a general concern for the lack of voice of people with intellectual disability, and a concern that this group of people were becoming more excluded from service support. CLA and WWILD-SVP had observed that within the new 'specialised' disability service sector in Queensland, the needs of people with an intellectual disability were not being recognised and that many were 'falling through the cracks'. People with an intellectual disability are now becoming more apparent and obvious in the criminal justice system, crisis homelessness response system, child safety and tertiary health response, and mental health system.

In 2011 the first Queensland Roundtable event was held, focusing on issues such as physical and mental health, ageing, involvement in the criminal justice system as victims or offenders, homelessness, and involvement in the child safety system. This event was very well attended from across the disability and mainstream service sector.

### *The 2012 Roundtable: "Breaking Ground: The NDIS and Intellectual Disability"*

In 2012 the Working Group expanded to include Endeavour Foundation, and some workers and academics from the university, mental health and disability support sectors. The decision was made to focus the 2012 Roundtable event on the emerging National Disability Insurance Scheme (NDIS), due to concerns that the NDIS could fail to recognise and identify the supports people with intellectual disability require to live in the community. The aim of the 2012 Roundtable was to raise general awareness and provoke debate, discussion and critical analysis within the key areas of assessment, eligibility, and self-management of funding.

This submission is the result of this event, and it presents recommendations from the Working Group, short papers written by the presenters for the event, and a summary of written feedback provided by the audience who attended the event.

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# 1. Recommendations for an NDIS from the Working Group for the Queensland Roundtable on Intellectual Disability

## 1.1 Appropriate Assessment for an NDIS

### *Functional assessment tools*

- The Inventory for Client Agency Planning (ICAP) and assessment tools with similar limitations should not be used as part of the NDIS ‘tool kit’ for assessing the support needs of people with intellectual disabilities.
- Assessors need to be aware that a person may experience multiple disabilities that can impact upon them in the assessment process, for example that a hearing impairment may impact more upon their participation in the assessment process than a mild intellectual disability.
- Where self-reporting is utilised in assessment processes, the information gathered needs to be verified by third parties who know the person well, to ensure the accuracy of the responses provided.
- People conducting assessments should be appropriately qualified and experienced with working with people with intellectual disability. This process should not be subject to economic imperatives of saving money.
- The NDIS assessment system needs to incorporate formal structures and processes for complaint and redress in the event that an individual or their family considers that their assessment was not accurate.

### *Some principles for assessment under an NDIS*

The Working Group argues that assessment tools under an NDIS need to:

- Be based on the UN Convention on the Rights of Persons with Disabilities and the social model of disability, specifically the principle that everyone has a right to engage in community and citizenship. The goal or outcome of assessment should be to ensure that people with an intellectual disability are supported to have valued roles and make a meaningful contribution to their community and society.
- Be flexible enough so that an individual or their family/carers can update their assessment if their situation changes. Support systems need to be similarly flexible to accommodate changing support needs.
- Be coordinated across different systems and mainstream services like education, housing, health and Centrelink. It is traumatic and time consuming for people to have to undertake multiple assessments every time a new organisation or department is approached for assistance.

## 1.2 Eligibility and Access to Mainstream Services

### *Referral to Mainstream Services*

- There is a need for a comprehensive database of services to be developed, utilising local knowledge of available services as much as possible.
- The Working Group supports a case management approach to assisting people with intellectual disabilities to access mainstream services.

### *Responses to Mainstream Services*

- The current mainstream service systems need sector development to adequately identify and adjust service delivery to meet the needs of people referred through Tier 2 of the NDIS.
- Mainstream service providers need to be encouraged to meet the Disability Service Standards, and to self-audit their achievement in meeting these standards. In referral processes and in the proposed database of services (see above), preference should be given to services that are shown to meet the Disability Service Standards.
- Mainstream services should utilise intake processes to identify clients with an intellectual disability therefore ensuring appropriate resources are developed and utilised.
- A centralised, freely available database of Easy English resources that service providers could refer to could be one cost-effective way to make small improvements to service delivery.
- Mainstream services working with people with intellectual disabilities need to remain flexible to work with people for as long as needed and in the ways that are needed.

### *Employment Services*

- In the experience of the Working Group, people with intellectual disabilities place high value on employment, earning an income, and contributing to their society and community.
- More support for alternative employment models, other than the current Disability Employment Services system, would encourage more marginalised people with intellectual disabilities to engage in the employment market and in their community.

## 1.3 Models for Self-Management of Funding

### *Capacity building and self-advocacy*

- Policy frameworks within the NDIS that acknowledge the need for meaningful input, control and choice for people with an intellectual disability, and incorporate appropriate safeguards to preserve these rights.
- Support and capacity building for People with Intellectual Disability to enable them to develop the understanding, skills and confidence to manage their funding and determine which supports are right for them.

- It is essential under an NDIS for all information about managing funding, getting assessments, and support options to be provided in Easy English versions that maximise understanding for people with intellectual disabilities.
- Funding be earmarked to support self-advocacy organisations and to develop a self-advocacy movement in States where such organisations are absent.

### **Safeguards**

- Formal structures and processes are required to ensure that people with disabilities and/or their families can easily access support if they are being exploited by a service provider, family member or carer.
- Adequate mechanisms are required to enable individuals, carers and family members to make complaints about service providers and for those complaints to be acted upon immediately.

### **Families and carers**

- Capacity building for families and carers to enable them to develop understanding, skills and confidence to support their family member's decision-making and management of funding.

### **Service providers**

- Capacity building for service providers to assist them to work in ways that shift the balance of power and maximise people's control and choice.
- Accountability structures to ensure that service providers support choice and use funds appropriately to support people's chosen outcomes.

### **Brokerage agencies**

- Quality controls and industry regulations to ensure that new brokerage agencies deliver transparent, high quality support, and can demonstrate specialist expertise and value for money.
- Fees for brokerage services need to be regulated and standardised across the NDIS system

## 2. Overview of Roundtable Event: “Breaking Ground: The NDIS and Intellectual Disability”

The proposed National Disability Insurance Scheme (NDIS) represents the most significant and comprehensive change for people with a disability in Australia. The NDIS promises to transform the way that services are funded and delivered, leading to better support and more control and choice for people with a disability.

The Working Group strongly supports the introduction of the NDIS to meet the needs of all people with intellectual disability. The Working Group has identified specific areas in the conceptualisation of the NDIS which require attention in order to ensure that people with an intellectual disability do not fall through the cracks in the process. People with an intellectual disability are one of the largest groups of people with a disability. Historically people with an intellectual disability have been an extremely disadvantaged and socially excluded group. Current data indicates that this disadvantage remains.<sup>1</sup>

The Working Group argues that a key benchmark for success of the NDIS will be whether it successfully includes and supports people with an intellectual disability to experience an adequate standard of living that would allow meaningful and positive participation in community life.. Meeting this benchmark would require a significant diminution in the prevalence of high unemployment, high rates of physical, financial and sexual victimisation, high rates of homelessness, high rates of imprisonment and juvenile detention, high rates of mental and physical illness, high rates of removal of children from parents with intellectual disability into state care, and a meaningful increase in positive participation in community life.

With these concerns in mind, the Working Group chose to focus on specific issues relating to the NDIS and intellectual disability at a Roundtable event in order to generate awareness and debate around these issues. The Roundtable was a half day event held on 23<sup>rd</sup> April 2012 at the Toowong Rowing Club, St Lucia, Brisbane. The event targeted service providers and policy makers. Prior to the Roundtable, members of the Working Group scoped possible priority issues by talking with service providers and advocates in Queensland and New South Wales, and conducting background research. Three major topics were identified and selected for exploration during the Roundtable event, and a presenter and a respondent were selected for each topic. Topics and presenters are outlined below:

### 1. Appropriate assessment for an NDIS

- Presenter: Mark Pattison, *National Council for Intellectual Disability*
- Respondent: Helen Fergusson, *Department of Communities, QLD Government*

### 2. Eligibility and access to mainstream services

- Presenter: Karyn Walsh, *Micah Projects*
- Respondent: Bob Gilkes, *Uniting Care Community*

### 3. Models for self-management of funding

- Presenter: Yvette Proud, on behalf of the self-advocacy group *Speak Out Reach Out* & NSW Council for Intellectual Disability
- Respondent: Fran Vicary, *Queenslanders with Disability Network; NDIS Advisory Group*

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<sup>1</sup> For example, see: Emerson, E., & Hatton, C. (2007) Poverty, socio-economic position, social capital and the health of children and adolescents with intellectual disabilities in Britain: A replication. *Journal of Intellectual Disability Research*, 51, 866–874.

Presenters were asked to prepare a short paper relating to their topic, which they submitted to the respondent prior to the event. On the day, the Roundtable proceeded according to the following structure: for each topic, presenters spoke for 20 minutes, followed by respondents who spoke for 10 minutes. The audience were then given 10 minutes to talk amongst themselves to identify major issues and questions, which they were asked to record on a feedback sheet. A facilitator then fielded questions from the floor.

Around 150 people attended the event with the majority of people providing positive feedback about the discussion and learnings experienced at the event. Amongst attendees and presenters there was hope and also concern about the changes the NDIS will bring. The presentations and responses provoked thought and discussion about the aspirations of people with disability to live in an inclusive society. Feedback from the audience indicated that the event improved people's general awareness of some key issues. However, it was very clear that further debate and discussion, particularly around the finer detail of how the NDIS will work, is still required. Written feedback forms were collected after the event, and the audience responses were collated.

This report presents three statements from the Working Group that relate to the three Roundtable topics. These statements draw on the presentations, respondents and audience feedback but have been further developed by the Working Group. The presenter's papers are provided in full in Appendix B. A summary of feedback from the Roundtable audience is presented in Appendix C.

### 3. Roundtable Working Group Statement: “Appropriate Assessment for an NDIS”

#### 3.1 Functional assessment tools

The Roundtable Working Group’s concern regarding assessment comes out of our experiences of supporting people with intellectual disability through the new assessment process in Queensland which started in June 2011. This new process uses the Inventory for Client and Agency (ICAP) assessment tool, which is a functional assessment that requires people to self-report the nature and impact of their disability to the assessor. Anecdotally, the ICAP assessment is traumatising for individuals and their carers, due to the requirement for people to explain how disabled they are.

There is little evidence that this type of assessment accurately determines a person’s functional support needs. Functional assessments, like the ICAP and various tests that measure Intelligence Quotient (IQ) also do not measure adaptive behaviours appropriately. Disability and Community Care Services stopped utilising the ICAP assessment for parents and carers in late 2011. A replacement assessment tool has yet to be identified for parents and carers; however, the ICAP has continued to be used for people with intellectual disabilities.

The Working Group questions whether the ICAP can adequately assess the capacity of a person with intellectual disability to manage their physical and mental health, risk of exploitation and exploitative relationships, levels of literacy, numeracy and communication, ability to maintain stable housing and employment, experience supportive positive relationships, and hold valued social roles in the community.

Self-report assessment tools such as the ICAP have questionable validity when used with people with intellectual and cognitive disabilities who may have difficulty with speaking, communicating or articulating the difficulties that they do have. The Working Group argues that:

- **The Inventory for Client Agency Planning (ICAP) and assessment tools with similar limitations should not be used as part of the NDIS ‘tool kit’ for assessing the support needs of people with intellectual disabilities.**

Assessment tools under an NDIS need to be sensitive to different types of disabilities. Assessment frameworks also need to recognise that people with intellectual disability frequently experience more than one type of impairment. Combinations of hearing and vision impairments, cerebral palsy, autism spectrum disorder, Fragile X syndrome, Down syndrome, acquired brain injury, and intellectual disability all affect cognitive capacity and the ability to self report in different ways.

- **Assessors need to be aware that a person may experience multiple disabilities that can impact upon them in the assessment process, for example that a hearing impairment may impact more upon their participation in the assessment process than a mild intellectual disability.**

People with intellectual disabilities experience much stigma in our community for being ‘disabled’ and have a tendency to mask their disability. In addition, people with intellectual disability can be prone to acquiescence and suggestibility, which means they are likely to agree with whatever the interviewer says even if they do not understand what is being asked.

For instance, the ICAP involves a series of questions that need to be answered with a numerical score. For example, one anecdotal example of a question asks: “Can the person stand on one foot for XX seconds”. Answer options range from 0 – never/has tried; 1 – can do but not very well (25% of time); 2 – does well most of the time; and 3 – can do all the time. This combination of two abstract ideas (remembering a specific physical function, and translating this into a numerical score) is extremely difficult for a person with an intellectual or cognitive disability to understand and answer.

While the Working Group strongly supports the right to self-determination and the participation of people with intellectual disabilities in the creation of their individual support plans the Working Group argues that:

- **Where self-reporting is utilised in assessment processes, the information gathered needs to be verified by third parties who know the person well, to ensure the accuracy of the responses provided.**

Masking the extent of disability, and a tendency towards acquiescence and suggestibility are issues specific to people with an intellectual disability. Many disability and mainstream services are unaware of this and do not take this into account during assessment. Assessment will function as the gateway into individualised funding under an NDIS, and the Working Group argues that:

- **People conducting assessments should be appropriately qualified and experienced with working with people with intellectual disability. This process should not be subject to economic imperatives of saving money.**

Cognitive capacity and competency need to be taken into account when deciding which tool is appropriate for each person and the Working Group is concerned how this will be determined and regulated under the NDIS. To safeguard against inappropriate assessment, the Working Group argues that:

- **The NDIS assessment system needs to incorporate formal structures and processes for complaint and redress in the event that an individual or their family considers that their assessment was not accurate.**

### **3.2 Principles for assessment under an NDIS**

The Working Group argues that assessment tools under an NDIS need to:

- **Be based on the UN Convention on the Rights of Persons with Disabilities and the social model of disability, specifically the principle that everyone has a right to engage in community and citizenship. The goal or outcome of assessment should be to ensure that people with an intellectual disability are supported to have valued roles and make a meaningful contribution to their community and society.**
- **Be flexible enough so that an individual or their family/carers can update their assessment if their situation changes. Support systems need to be similarly flexible to accommodate changing support needs.**
- **Be coordinated across different systems and mainstream services like education, housing, health and Centrelink. It is traumatic and time consuming**

**for people to have to undertake multiple assessments every time a new organisation or department is approached for assistance.**

## 4. Roundtable Working Group Statement: “Eligibility and Access to Mainstream Services”

The Roundtable Working Group supports the principle that all people with any level of intellectual disability who require support to live good lives in the community should have access to the individualised supports they require.

It is estimated that a total of 410, 000 people with a disability will receive Tier 3 individualised funding under the NDIS.<sup>2</sup> In 2003, there were a total of 2.6 million people aged 0-64 years with disability in Australia.<sup>3</sup> Of these, 436, 200 people aged 0-64 years had an intellectual disability.<sup>4</sup> These data mean that there will be many people with an intellectual disability who will not be eligible for individualised funding under the NDIS.

### 4.1 Referral to mainstream services

The referral process and structure for those not eligible for individualised funding is vital for people with disabilities to successfully access mainstream services. The Working Group argues that:

- **There is a need for a comprehensive database of services to be developed, utilising local knowledge of available services as much as possible.**

Such a database would include information about smaller community organisations that can provide more flexibility and specialised service as well as larger service providers and government departments. Information about the accessibility of each service for people with intellectual disabilities will need to be included. In addition, provider’s knowledge of and compliance with the Disability Service Standards ‘good practice’ benchmarks for working with people with intellectual disability should be included. In addition:

- **The Working Group supports a case management approach to assisting people with intellectual disabilities to access mainstream services.**

People with intellectual disabilities often require more assistance to successfully access services. This may be due to the implications of their disability for planning and problem-solving skills. Many people also lack confidence in speaking to organisations over the phone and explaining what they need. A case management approach would provide the required flexibility and problem-solving support to enable people with intellectual disabilities to make and sustain contact with mainstream services.

### 4.2 Responses from mainstream services

The Working Group is concerned that despite recent improvements to the way that mainstream services respond to vulnerable people with intellectual disability, that responses still require development. Mainstream systems, including health, homelessness, and domestic violence services, often lack the specialist knowledge required to effectively support people with an intellectual disability, particularly those with ‘mild’ and borderline disabilities who may or may not be identified. The Working Group argues that:

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<sup>2</sup> Productivity Commission (2011). *Disability Care and Support*, Report no. 54, Canberra.

<sup>3</sup> Commonwealth of Australia (2011). *National Disability Strategy 2010-2010 Evidence Base*.

<sup>4</sup> AIHW (2008). *Disability in Australia: Intellectual disability*. AIHW bulletin no. 67. Cat. no. AUS 110. Canberra: AIHW.

- **The current mainstream service systems need further sector development to adequately identify and adjust service delivery to meet the needs of people referred through Tier 2 of the NDIS.**

Part of the Tier 1 campaign of improving community attitudes and understanding of the experience of people with disabilities should be aimed at encouraging mainstream services (government and non-government) to improve their awareness and quality of response to people with intellectual disability and impaired cognitive capacity generally. The Disability Service Standards are currently voluntary benchmarks of 'good practice' for non-disability specialist services.

- **Mainstream service providers need to be encouraged to meet the Disability Service Standards, and to self-audit their achievement in meeting these standards. In referral processes and in the proposed database of services (see above), preference should be given to services that are shown to meet the Disability Service Standards.**
- **Mainstream services should utilise intake processes to identify clients with an intellectual disability therefore ensuring appropriate resources are developed and utilised.**

Further, people with an intellectual disability often struggle to negotiate and understand a system where information is not presented in a way that is easily understood or adequately addresses their needs. Many government and non-government agencies have created Easy English resources on different topics. The Working Group argues that:

- **A centralised, freely available database of Easy English resources that service providers could refer to could be one cost-effective way to make small improvements to service delivery.**

Finally, while a case management approach would address some of these issues, and engage family and informal carers in assisting people with disabilities to access services, there is still a need for greater flexibility in mainstream service systems in working with people with intellectual disabilities. People with intellectual disabilities need longer engagement periods with workers and higher levels of support than many service providers are funded to provide in order to achieve the same outcomes as with those without disabilities. They may also struggle to meet the financial costs where the full cost is not covered by Medicare. The Working Group argues that:

- **Mainstream services working with people with intellectual disabilities need to remain flexible to work with people for as long as needed and in the ways that are needed.**

### 4.3 Employment services

The employment sector also needs development to enable people with mild and borderline disabilities to access work. Disability employment services are currently useful for people with physical disabilities, but have low success rates with assisting people with intellectual disabilities to find lasting employment.

- **In the experience of the Working Group, people with intellectual disabilities place high value on employment, earning an income, and contributing to their society and community.**

Alternative models such as community-based initiatives that support people into employment utilising local knowledge and networks are often successful methods of connecting people with 'mild', 'moderate' and 'borderline' intellectual disabilities with employment. These may involve supported workplace models and social enterprises, or small niche-market projects where individuals are supported in the initial stages of setting up a small business and finding a market for their output. The Working Group argues that:

- **More support for alternative employment models, other than the current Disability Employment Services system, would encourage more marginalised people with intellectual disabilities to engage in the employment market and in their community.**

## 5. Roundtable Working Group Statement: “Models for Self-Management of Funding”

The Roundtable Working Group supports the principle of self-management of funding for people with a disability. All people with a disability should have the right to maximum control and choice in relation to the support that they receive. The Working Group is concerned that issues relating to self-management of funding for people with an intellectual disability have not received sufficient attention. In particular, there is a need for capacity building for individuals, families and service providers, and sufficient safeguards.

### 5.1 Capacity building and self-advocacy

People with an intellectual disability will generally need support in order to understand the service options available to them, the consequences of their choices, and to successfully communicate their choices to others. The Working Group argues that there is a need for:

- **Policy frameworks within the NDIS that acknowledge the need for meaningful input, control and choice for people with an intellectual disability, and incorporate appropriate safeguards to preserve these rights.**

People with an intellectual disability have traditionally been regarded as lacking the necessary capacity and/or as too vulnerable to make important decisions about their lives. They have often not had the opportunity to participate in problem-solving and decision-making. This means that they often lack the necessary experience, skills and confidence to make decisions and to successfully manage their funding. The Working Group argues that there is a need for:

- **Support and capacity building for people with intellectual disability to enable them to develop the understanding, skills and confidence to make good decisions, manage their funding and determine which supports are right for them.**

People with an intellectual disability need support to learn how to:

- identify concerns and problems
- know who to speak to and how
- be confident enough to speak up
- improve self confidence and self esteem
- have independent control over their lives
- have dignity and self respect
- have the strength to guard against exploitation and abuse
- have power as an individual with rights<sup>5</sup>

People with an intellectual disability often experience difficulties understanding important information. The Working Group argues that:

- **It is essential under an NDIS for all information about managing funding, getting assessments, and support options to be provided in Easy English versions that maximise understanding for people with intellectual disabilities.**

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<sup>5</sup> <http://www.valid.org.au/>

This would align with Article 9 of the UN Convention on the Rights of People with Disabilities, to which Australia is signatory, the right to accessible information.

Independently funded self-advocacy organisations play an important role in supporting people with intellectual disability to understand their rights and speak up for themselves. Self-advocacy organisations can provide training to enable people to develop skills and confidence in decision-making, speaking up, and managing funding, and provide independent advocacy support when necessary. Currently there are no independently funded self-advocacy organisations in Queensland. The Working Group argues that:

- **Funding be earmarked to support self-advocacy organisations and to develop a self-advocacy movement in States where such organisations are absent.**

## 5.2 Safeguards

People with intellectual disability are vulnerable to exploitation and the United Nations Convention on the Rights of Persons with Disabilities specifically charges governments to “take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse”.<sup>6</sup> The Working Group argues that:

- **Formal structures and processes are required to ensure that people with disabilities and/or their families can easily access support if they are being exploited by a service provider, family member or carer.**

It is critical that an NDIS recognises and supports the role of The Adult Guardian and Public Trustee across all Australian states in protecting and supporting the rights of people with an intellectual disability to exercise maximum control and choice in the management of their funding. The Working Group also argues that:

- **Adequate mechanisms are required to enable individuals, carers and family members to make complaints about service providers and for those complaints to be acted upon immediately.**

Currently there is no Ombudsman in Queensland and the Disability Services complaints mechanisms are not adequately resourced. An independent Ombudsman position should be created for people with intellectual disability (or all areas of disability) that would receive complaints, act on those complaints, and take legal action against services as required.

Further discussion and analysis needs to occur around the issue of helping people make good decisions in the management and direction of their own funding. Mechanisms should be developed to help people to manage their funding in appropriate and effective ways.

## 5.3 Families and carers

Families and carers often play an important role in the lives of people with an intellectual disability, including by providing unpaid support. Under an NDIS, families and carers may play an even greater role in supporting their family member’s decision-making, fund management, and support coordination. The Working Group argues that there is a need for:

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<sup>6</sup> United Nations (2006). *Convention on the rights of persons with disabilities (UNCPRD)*, Department of Economic and Social Affairs, United Nations. Article 16, page 12.

- **Capacity building for families and carers to enable them to develop understanding, skills and confidence to support their family member's decision-making and management of funding.**

#### 5.4 Service providers

The NDIS represents a significant shift in the way that service providers support people with an intellectual disability. The Working Group argues that there is a need for:

- **Capacity building for service providers to assist them to work in ways that shift the balance of power and maximise people's control and choice.**
- **Accountability structures to ensure that service providers support choice and use funds appropriately to support people's chosen outcomes.**

#### 5.5 Brokerage agencies

Some people with an intellectual disability and their families and carers may choose to employ the services of a brokerage agency to manage funding on their behalf or to provide administrative and coordination support. The Working Group expects that the NDIS will prompt an increase in brokerage agencies, and that many of them will be for-profit. The Working Group argues that there is a need for:

- **Quality controls and industry regulations to ensure that new brokerage agencies deliver transparent, high quality support, and can demonstrate specialist expertise and value for money.**

The Working Group questions the ethics of charging fees for brokerage services. Such fees will reduce the total amount of funding available for support and may disadvantage individuals with particularly high support needs, and individuals who already live in poverty. It is critical that industry regulations also include strict guidelines to guard against excessive fees.

- **Fees for brokerage services need to be regulated and standardised across the NDIS system.**

## Appendix A – Brief description of Roundtable Working Group organisations

### *Community Living Association (CLA)*

Community Living Association was established in 1989. CLA Inc. supports people with Intellectual Disability who are experiencing significant social disadvantage to become fully accepted members of the community. CLA Inc. has particularly focused on supporting people with Intellectual Disability around issues of safety and living free from exploitation, working with homeless people with Intellectual Disability, creating fulfilling and valued social roles, and supporting the physical and mental health of people with an Intellectual Disability.

### *WWILD-SVP Association Inc. (WWILD)*

WWILD works with people with intellectual and learning disabilities that have experienced or at risk of experiencing sexual violence or have become a victim of crime. The organisation was established in 1995. It developed out of group of young women with intellectual disability who had come together around their experiences of sexual violence. The organisation further developed to support Victims of Crime with Intellectual Disability.

**The Sexual Violence Prevention Program** provides support to women with intellectual and learning disabilities aged over 15 who have experienced or are at risk of experiencing sexual violence.

**The Victims of Crime program** provides support to people with learning and intellectual disabilities who are a victim of crime and the professionals seeking to support them.

### *Endeavour Foundation*

Endeavour Foundation was founded in 1951 by a group of mothers who wanted their children with an intellectual disability to receive education. Endeavour Foundation is now one of the largest non-government disability service providers in Australia, supporting more than 3,350 people with a disability, from 230 locations in Queensland and New South Wales. Endeavour strives to provide opportunities for people with a disability so they may participate in the everyday life of the community. To this purpose, a range of services are offered including supported accommodation, aged support, children focused services, employment opportunities, education programs in literacy, technology and social skills, and lifestyle opportunities.

## Appendix B – Roundtable Presenter Papers

### Topic 1: Appropriate assessment tools for an NDIS

*Presenter: Mark Pattison, National Council for Intellectual Disability*

#### **Breaking Ground: The NDIS and Intellectual Disability: Appropriate Assessment Tools for an NDIS**

**OR: People with intellectual disability “leading lives that they have reason to value”  
Outline of Presentation - 8 questions and challenges in 8 pages**

In thinking about this topic I was reminded of the quote by A Sen “leading lives that they have reason to value”. In using the quote by A Sen I often add, ‘and lives that others have reason to value’. At the same time an article by John O’Brien came across my desk.

John O’Brien recounts the story of the life of Nina which I have reproduced below. As I, and you, read her story the question in relation to this topic is, what assessment (and funding attached to that assessment) would enable this degree of citizenship? The questions that Nina’s story raises will be the content of my presentation!

***Question No 1. What assessment tools would enable Nina, her family and allies to successfully be a contributing member of her community, i.e, citizenship?***

Making a home

The test of a successful support organization and a successful service system is its capacity to respond constructively to the demands for innovation originating in the relationships between people with intellectual disabilities, their families and allies and those who support them.

For most of the past 25 years, Nina lived, as many people with intellectual disabilities do, in a service controlled space managed by people with no commitment to social innovation. Forced by heroic family advocacy, authorities placed her out of an horrific institution into a smaller scale, more highly staffed, more closely inspected group home specialized for people with profound disabilities. For a long time, the implicit question that organized her life was “How can we reduce the number of reported incidents and complaints involving her?” Good answers to this narrow question were hard to come by, despite continuing family advocacy, extensive professional involvement and very substantial expenditures on services.

As a stronger circle of support gathered with Nina and her family and connected her parents to service leaders committed to social innovation, a new question emerged, “How might Nina show up as a person comfortably at home?”. This question opened a gap by challenging the unspoken assumption that treated Nina as though the source of her unrest were a flaw in her instead of the inevitable result of the way she was served. Considering the situation from this new perspective highlighted different realities and provided a way to understand her life as locked in by lack of attention to her uniqueness. The circle began to consider the consequences to Nina of other people’s difficulties in understanding her communication, which does not rely on words, and inattention to the interactions of her particular experience of space and time on her neurophysiology.

This new frame for Nina’s experience made plain what had been obscured by repeated and frustrating efforts to make the group home work. The group home, with its cacophonous congregation of people whose sensitivities are driven over the limits of self-control by one another’s outbursts, its attempts at management through group routine, control by impossibly

complex behaviour plans, and culture of compliance and surveillance could never be anyone's home. The next step had to be developing a place with the potential to actually be Nina's home. This process of social invention began with figuring out the set of relationships, spaces and routines responsive enough to allow her family and her allies to learn with Nina what "comfortably at home" might look like.

Despite repeated endorsement of person-centeredness and a vision statement that endorses choice in living arrangements, the system that Nina and her family rely on does not offer a pathway for people with significant need for support to join those who know them best and design the exact assistance they need inhabit their own homes. Indeed, the system's structure and mode of management imposes significant drag on any social innovation. Some of this drag is the product of history: powerful assumptions about people's limitations define placement and staffing patterns; community service providers are heavily invested in real estate and labour contracts tied to group settings that residents must fit into; staff and management have no encouragement to imagine better. Some drag results from a profound mis-match between the demands of learning required to create pathways to better lives and a system that demands compliance to ever more detailed regulations and contract requirements because it sees them as necessary to manage risk, assure health and safety and control expenditures. Collaboration with a support organization willing to generate the means to develop a home with Nina and her allies and manage the boundary with the service system made it possible for her to move into a space where being comfortably at home was a possibility.

Each social innovation opens the way for the next. A new setting provided the space for a deeper exploration of what is meaningful for Nina about home and neighbourhood life. A gifted practitioner, deeply committed to what she has called Gleaning Possibilities, brought her perspective to Nina. Her view of Nina's neuro-physiology has opened new possibilities. While those who know Nina well agreed that she liked music, no one had imagined the extent to which music could be a resource to her. Her capacity to respond to carefully chosen rhythm and tempo has given her deeper relaxation and more fluent movement. Music has also provided a theme for her household as she invites young family members and friends to practice their instruments, hosts music evenings, and employs a graduate student at a nearby university to coach her in a deeper appreciation of music. It also shapes her neighbourhood engagement as she explores a variety of performance venues. One innovation at a time supports Nina to show up more comfortably at home. There are many more possibilities for her to experience meaningful time away from home as her journey with her co-innovators continues.

*Excerpt from an article to be published in **Interaction** May 2012*

**Question No 2. What assessment tools will ensure that people with intellectual disability have their right to participation in political and public life?**

**Exemplar for my presentation**

In considering an illustration of the arguments that I wish to make I have chosen to use Article 29 of the UN Convention on the Rights of Persons with Disabilities;

Article 29 - Participation in political and public life

States Parties shall guarantee to persons with disabilities political rights and the opportunity to enjoy them on an equal basis with others, and shall undertake to:

- a. Ensure that persons with disabilities can effectively and fully participate in political and public life on an equal basis with others, directly or through freely chosen representatives, including the right and opportunity for persons with disabilities to vote and be elected, inter alia, by:
  - i. Ensuring that voting procedures, facilities and materials are appropriate, accessible and easy to understand and use;
  - ii. Protecting the right of persons with disabilities to vote by secret ballot in elections and public referendums without intimidation, and to stand for

- elections, to effectively hold office and perform all public functions at all levels of government, facilitating the use of assistive and new technologies where appropriate;
- iii. Guaranteeing the free expression of the will of persons with disabilities as electors and to this end, where necessary, at their request, allowing assistance in voting by a person of their own choice;
- b. Promote actively an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs, without discrimination and on an equal basis with others, and encourage their participation in public affairs, including:
  - i. Participation in non-governmental organizations and associations concerned with the public and political life of the country, and in the activities and administration of political parties;
  - ii. Forming and joining organizations of persons with disabilities to represent persons with disabilities at international, national, regional and local levels.

The reason I have chosen Participation in Political and Public Life is because it is never a consideration for people with intellectual disability, beyond enrolling them to vote. Yet, it is an Article in the UN Convention and the UN Convention and all its Articles apply to all people with disability including those who 'require more intensive supports'.

***Question No 3. To what degree are Australian Governments prepared to fulfill the human rights of people with disability, as set out in all the UN Conventions and Covenants; or will the NDIS only support the basic requirements of life (core activities)?***

The NDIS, we are told, will be transformative for people with intellectual disability and their families, an indication of whether it is or not and to what degree will be in the response to the above question.

This is obviously a challenge. Very few current assessments would even consider political and public life with their concentration on 'functional (dis)ability', can you do x or y, beyond a single question as to whether a person is enrolled to vote. How many of the current assessment tools have even this question?

The National Disability Strategy states:

The Strategy will play an important role in protecting, promoting and fulfilling the human rights of people with disability. It will help to ensure that the principles underpinning the Convention are incorporated into policies and programs affecting people with disability. (p 9)

***Question No 4. How will NDIS assessment tools take into account the modern conception of disability; and how will this be reflected in funding?***

The conception of disability has changed dramatically over the last two decades starting with the development of the International Classification of Functioning, Disability and Health (ICF).

Historically disability was seen as a 'problem' that was solely within the person and that the person had to be cured, and/or managed. The response was frequently the segregation of people with disability from the community in congregate or isolated settings (including the family home). With the challenge for people to be involved in their community came the awareness that while a person has an impairment their participation in community life was not enabled by placing the focus solely on them. The environment, physical, social and attitudinal, also played a part and in many instances was a major factor in a person's

disability, i.e. disability is an interaction between a person with an impairment and their environment(s).

It is interesting to note that the ICF has the following domain; Community, Social and Civic Life and the sub-domain, d 940 Political Life and Citizenship: engaging in the social, political, and governmental life of a citizen ...

***Question No 5. Can and should we change the language that we use to describe the purpose of the NDIS, and by association NDIS assessment tools?***

Before we can talk about or design an assessment tool we must begin the evolution of the language or more correctly to continue the evolution of the language and concepts that has been taking place over the last decade.

The NDIS must be seen as a radical revolution (a tautology?), not as a reform! The challenge is to see a different future not one which merely tries to 'fix a broken system'; a future of citizenship for people with disability not as service users.

It is not about, as a national campaign tries to convince us, 'revolutionising disability services'. It is about citizenship for people with intellectual disability, it is about real lives - lives that people with intellectual disability "have reason to value".

A constant refrain that I hear these days is that the person talking "gets it"! The "it" being the NDIS revolution. I have heard numerous politicians, bureaucrats and service providers proudly announce that they know what the future will look like and how to make it 'real' for people with disability. Beware, no-one "gets it" and that includes me!

A sure way of knowing that a person does not "get it" is when they talk about the NDIS and the future using service language, e.g. clients, quality assurance, unit costs, functional assessments, etc, etc.

***Question No 6. To what degree has the change of language to person-centeredness promoted a change in practice?***

There is an argument that the NDIS should be only about the person with disability and address their specific support needs, i.e., self help, mobility and communication. Citizenship and human rights are beyond the scope of the NDIS and are better addressed through the National Disability Strategy. I am not one of these!

As Nina's story shows assessments and funding decisions are not divorced from the real world and they will either, directly or indirectly (e.g., attitudes) constrain or enable a person's life in the community. There is also the question of the investment of the community's funds, what does the community get back?

Citizenship is important as it not only confers rights but also responsibilities, a responsibility to contribute.

Currently assessments centre on the person and their impairments, increasingly placing people in neutral environments, and attempt to quantify the support that a person needs to overcome their impairments. But a wheelchair alone will not enable a person with a physical disability to catch inaccessible transport and being enrolled to vote will not ensure that a person with intellectual disability is engaged in the political life of their community. Each begins the process but they must not be seen as an end in themselves; this is what current functional assessments do.

Current language is centred on the individual with disability, 'person centeredness', and there will be many who will advocate self-assessment tools for the NDIS. These have been and are important in moving away from service orientated assessments and in creating flexibility and creativity in how people are supported but they are not the end of the assessment road.

***Question No 7. What assessment tool (including self-assessment assessments) places an obligation on a person to make a tangible contribution to their community? How many people with disability, who have had assessments are making a tangible contribution to their community?***

The reason why Nina's story made me stop and think was not her change of circumstances, there are many (and yet too few) stories such as hers, but her fulfilling her obligation to contribute to her community - her community was tangibly better for her being a member of it! Surely a life that she has 'reason to value' and a life that we would all have a 'reason to value'.

For me this is the real challenge! The UN Convention and the ICF challenge us to see the person with intellectual disability within their community. If we are to respect the person with intellectual disability then we must have **assessment tools that are not ends in themselves but act as one means of enabling citizenship.**

### **People with Intellectual Disability**

People with intellectual disability have a "significant limitation in 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"

Further, "limitations in intelligence should be considered in light of four other dimensions of human functioning: adaptive behaviour, health, participation and context."

AAIDD p.31.

***Question No 8. Is it possible to have a standardised assessment tool that enables people with intellectual disability to contribute to their community? If not, or if we are unwilling to design one, what are the implications for people with intellectual disability and Australia's obligations under the UN Convention?***

It is important to remember that intellectual impairment is the only disability that has a clear cut off, i.e. it does not have a continuum. Therefore, all people with intellectual disability have a significant disability. This is not understood by the general disability community and to a degree by the intellectual disability community.

The first implication of this was understood and acknowledged by the Productivity Commission when it stated that all people with intellectual disability should be eligible for an NDIS assessment. Secondly, 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.

People with intellectual disability can have physical, sight, hearing and other impairments in addition to their intellectual disability and these should be taken into consideration in any NDIS assessment. But, primarily any assessment has to take into consideration the person's

intellectual functioning in light of their adaptive behaviour, health, participation and context. To achieve this each assessment will (and must) be unique to the individual and their environments.

Using Article 29 the Right to Participation the Policy and Public Life, how will a NDIS assessment enable a person with intellectual disability to be aware of news events, community activity, political activity (policy statements, etc) and to participate to the degree that they want to.

People with intellectual disability present a real challenge to the NDIS to go beyond 'core activities'.

## **Conclusion**

What does this mean? If we are going to begin with the person and if we are going to give people control over their lives then this transformation begins at the beginning. It begins with the person and/ or their allies saying that they need assistance to be a valued member of their community, to contribute to the life of their community. It proceeds with them with or without assistance setting out their 'plan', how they are going to increase their skills, how they are going to be involved in their community, how they are going to contribute to their community and the support and assistance they will need to do all this.

Is this that hard? Many will want structured support to be able to do this, many are already doing it! The 'threat' of the NDIS is that this small degree of innovation and creativity will be overwhelmed by bureaucrats and service providers who are unable to cope with change and will impose the old many questioned functional forms.

"In practice conformist mediocrity is much more common than creative experimentation in state service delivery" (Tony Abbott)

I do not want to get into a false debate about accountability, fairness, and limited resources. For those who balk at the thought of transformation these are 'safe' areas which require no new thinking, they leave Nina in her large institution or at the very best in an incompatible group home.

I along with many others want the NDIS to break new ground. Self assessment based on planning is currently practiced both in Australia and internationally the question is, what is the next evolutionary step?

The answer I suspect lies within a struggle with the concept of citizenship. The concept of reciprocity of both taking from and giving to your community.

## **Key Speaking Points**

- The NDIS holds the promise of new ground being broken, of a transformation in the lives of people with disability. In the way people with disability will be supported and funded to have control over their lives
- More of the same will not be good enough; the culture must change from one of service users to one of valued lives. All assessment of people with disability, for the NDIS, must be based on citizenship not as users of services.
- The key concept is citizenship - people with intellectual disability will 'lead lives they have reason to value'

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Postscript: For NCID this Roundtable is important as it will draw together our thinking and prompt debate that will influence the design of the NDIS. The issue of assessment is for NCID the second most important issue with regard to the NDIS (the first being ensuring that the NDIS is funded adequately to meet all the needs of all people with disability). As the first step for an individual with with intellectual disability to get the assistance they want (and need) assessment will 'set the tone'. NCID does not have a firm view on what the assessment should be, hence our involvement in this Roundtable, though we do have a firm view on what it should not be.

## Topic 2: Eligibility and access to mainstream services

*Presenter: Karyn Walsh, Micah Projects*

### **Breaking Ground: National Disability Insurance Scheme: Eligibility and Access to Mainstream Services**

Micah Projects is a community organisation with an unswerving commitment to social justice. We believe that every child and adult has the right to a home, an income, healthcare, education, safety, dignity and connection with their community of choice. Micah Projects provides a range of support and advocacy services to individuals and families.

Our Mental Health and Disability programs include the Resident Support Program, Romiga and the Social Inclusion program. We also see people who have disabilities through our other programs such as Homelessness to Home Support Services, Forgotten Australians Support Services, Family Women Children Support Services, and Supportive Housing Services. Our disability program provides support for up to 20 people who have individualised funding ranging from 5 hours per week to 45 hours per week for people who usually have a combination of intellectual, psychiatric or physical disabilities. Our Homefront service is also funded through Disability Services to provide planned support to people (about 45 – 60 People) with a disability to sustain their tenancy and provide support for good quality of life including individuals and families. The Romiga service is 3 women in a shared tenancy with 24 hour support.

These services can involve access to Centrelink, housing, access to personal support services, access to health services e.g., physical and mental health assessments, the Adult Guardian and the Public Trustee, community service providers, and involuntary services. The aims of these programs is to facilitate Independence, Interdependence and Choice, Protection of Vulnerability and Abuse, Free from discrimination, Safety, Human Rights such as access to housing, healthcare, meaningful work, personal care and social support, Access to Entitlements, Support and engagement with family, friends and community, Ensuring access to Mainstream and Specialist Services, Facilitating choices of an individual to determine their quality of life, Social inclusion and Community, family, friends connection. What can happen when the work breaks down is individuals cannot remain within family and extended family; services do not have the resources and capacity to meet demand for services; individuals are left in isolation to try and manage the maze of services, obligations. Fragmentation of responsibility and service system; individuals have to pay for services and supported accommodation from their Disability Support Pension – left with very little resources on \$347.65 a week if over 20yrs and \$258.35 if under 20yr; and independent Individuals fall into the specialist homelessness service system and for years can be trapped in a system of emergency accommodation, boarding houses, on the street often resulting in time in prison, poor health, addictions, trauma, loss of contact with family and friends.

There are ways we can as mainstream services make some change and come up with solutions. These can include service system changes such as Adult Guardian, Public Trust, Advocates and Service providers can working together; more clearly defined roles and responsibilities between statutory and non-government community agencies, legislative changes, and greater shared knowledge and skill base for workers working with people with impaired capacity.

Themes in the evidence for appropriate accommodation solutions include:

- Building an integrated approach with formal linkages between housing, health and supportive services;

- In the USA and Canada Permanent Supportive Housing is recognised as evidence based approach to different populations;
- In UK Supporting People Program commenced in 2003 separating housing costs and costs of the support necessary to allow vulnerable adults to live independently.

There are also advantages and disadvantages of different housing/accommodation options: see below:

<b>Shared Tenancies with accommodation based support</b>	<b>Individual tenancies with floating support</b>
Danger of less individualised support	Fully individualised support
24 hr staff coverage sometimes possible	Limited number of support hours available each day
Maximum flexibility of support as staff are always at hand	Difficult to change support hours at short notice
Less privacy and time alone	More privacy and time alone
Less chance of being lonely	More chance of being lonely
Support and housing managed by the same organisation (often)	Clear separation between landlord and support provider
Possibility of minimising cost per hour of support	Potentially higher costs of support due to costs of travel time
System suited to the employment of full time staff – giving greater consistency of support	System suited to the employment of part time staff giving less consistency of support

Other Innovations for practice include the integrated Response with Queensland Health to enable responses to Dual Diagnosis of addictions, mental health and other primary health conditions and the impact of trauma. Also recognising the impact of childhood experiences of abuse, including the establishment of peer support initiatives and hubs as a base for people to connect and seek services when required including supported employment. We have also looked at establishing new Community Partners and Engagement so as to create pathways that are easier for individuals to engage, participate and seek assistance as required. Micah provides a range and mix of models and organisational responses that reflect supporting individuals aspirations, challenges and barriers.

### Topic 3: Models for self-management of funding

*Presenter: Yvette Proud, on behalf of Speak Out Reach Out & NSW Council for Intellectual Disability*

## QLD Roundtable on Intellectual Disability Models for self-management of funding

### Who are we?

Speak Out Reach Out is a subcommittee of the Board of the NSW Council for Intellectual Disability. All Speak Out Reach Out members have intellectual disability. NSW CID are systemic advocates. We work on the big issues effecting lots of people. Many members of Speak Out Reach Out are also Directors on the Board.

### How did we find out about self-managed funding and support?

In 2010 and 2011, Speak Out Reach Out made submissions to the Productivity Inquiry into Lifetime Care and Support for People with Disabilities. One of the reasons SORO decided to do this was to make sure voices of people with intellectual disability would be heard. Our experiences and views are often different from those of families and carers, and of service providers. We also wanted to make sure that the needs of people with low to medium support needs were properly understood, and not thought of as outside a new support system. We did lots of thinking and talking about how the Productivity Commission ideas could work for us

Since we have worked on the submissions, The NSW Government has asked NSW CID to do consultations with lots more people with intellectual disability around the state. The NSW Government wants to improve the way support happens too. They want to use "Person Centred Approaches". This is very similar to the ideas for the NDIS. It includes the option for people to choose to manage their own support packages.

### What did we find out?

NSW CID found that people had much the same views as we did about

- what this would be like,
- and what people would need to make this work.

These include:

**People really like the idea of having more flexibility and choice** about their support and services. They like the idea that they can have more control about how they live their lives.

**People know they have little experience** in many things that will become an option for getting support: big decision-making, more choices, managing a budget, hiring staff etc.

**They are clear that they and/or their families/carers will need training** on how to do these things for it to work.

**They want to make sure there are plenty of opportunities to get training, and also to learn through their experiences.** They would like people to have faith in them and their abilities to learn.

**People feel that it will be pretty hard for any of it to work without speaking up skills and decision-making skills. Another way to say this is 'self advocacy'.**

People with intellectual disability have experienced a lot of discrimination. Time is not taken to hear their views. They are often not taken seriously. The community and government assume that others will be there to make decisions – the right decisions - on behalf of people with intellectual disability. This means many people with intellectual disability stay more reliant on others than they may need to be. They don't develop their skills and confidence. They are not empowered. Even though an NDIS aims to shift decision-making and control of their lives to individuals, self advocacy training is not seen as important as we see it in making a new system work for people with intellectual disability themselves.

We know that the Productivity Commission said that advocacy in general should be funded outside the NDIS. We agree.

We know that the Productivity Commission said the new Disability Support Organisations should do some skills training and confidence building.

But there have been no more opportunities to have a say about how this should work since the Inquiry, or whether self-advocacy will be properly recognized and funded by government.

**We think that to make it work the government must keep people with intellectual disability involved in shaping the new system.**

Our presentation will talk about all these things. We will use video interviews with members of NSW CID to get our points across.

Yvette will support the development of the presentation. She will present it in Brisbane, and talk about some examples of where self-managed funding is now an option. In NSW, day programs/post schools programs now have the option of self-managed packages.

In Victoria the state's Auditor General reported on how self management is going there, and recommended some changes.

**Our presentation will also explain about why speaking up groups, independent from services providers, are important to success.**

## Appendix C – Summary of Feedback from Roundtable Audience

The audience feedback summaries draw on written feedback about the Roundtable topics collected on a feedback sheet and distributed to all attendees. The summaries below identify the main themes raised in relation to each topic, and supplement these with a selection of illustrative quotes.

### Topic 1: Appropriate assessment tools for an NDIS

#### **Assessment tools need to be effective**

*Will the assessment tools be self reporting based and therefore based on the cheapest practice as opposed to the right practice – self reporting assessments have not worked for Growing Stronger.*

*Functional assessments don't cover learning new skills or transferring skills when circumstances change e.g. moving house.*

*Combination of functional/formal assessment (reasonable and necessary) and self-assessment (choice, control, person centred, family centred)  
People with IQ score 70-84 with adaptive functioning deficit should automatically be included as having a significant disability under NDIS*

#### **Assessment processes need to be fair**

*Tools - Reasonable vs Necessary – who decides what is necessary for me. Not an assessment*

*In terms of funding levels, it would seem to make sense to fund as an overall 'needs' assessment. That is 'same for all'. Issue of funding after assessment is that families who manage better get less. E.g. autism L1 = \$\_\_\_; autism L2 = \$\_\_\_\_  
Concerns are that the assessment processes will be used as gate-keeping mechanisms that exclude those who do not have the skills or knowledge to position themselves well for funding.*

*Reasonable and necessary - if it is necessary, that should be the requirement - if it is needed then it is needed.*

#### **Assessment processes need to be respectful and consistent with Human Rights**

*Keep it relationship based so that assessment is responsive and dignity enhancing.*

*NDIS assessment needs to hold to all points of UN Convention [on the Rights of People with Disabilities]*

*How does assessment match to Article 29 UN Convention [on the Rights of People with Disabilities – Participation in Public and Political Life]*

*We need to remember a diagnosis or assessment does not equal a person and my fear would be that we reduce people to a category and rigidly impose rules relating to the category rather than flexibly engaging with people and their desires and needs.  
Assessment does not equal truth.*

### **The assessment process needs to be efficient**

*Will there be enough assessors to meet the demand or will people need to wait months and months to access support?*

*Bureaucracy should be limited.*

*How will the government policy on red tape reduction impact on assessment processes?*

### **Assessments need to be flexible to people's changing circumstances**

*Will there be the ability to alter the NDIS plan if circumstances change outside of any review?*

*Need to be aware of changing health needs of people as they get older*

### **Assessments should complement assessments in other fields of support**

*NDIS assessment should be multi-disciplinary and well-integrated with other assessments used in other domains - e.g. education, health etc.*

### **People with disabilities, families, carers and NGOs need to be consulted in developing assessments. In Queensland, these stakeholders do not feel included**

*Most NGO and carers or PWD have not had input into the Dyson Consultant report*

*Carers and families need to be involved in Building Blocks*

*Dyson Consulting needs to consult more widely*

## **Topic 2: Eligibility and access to mainstream services**

### **Better links between assessment and access are required. Appropriate assessment leads to appropriate access to mainstream services.**

*Different types of disabilities and life circumstances affect people's capacity to engage in assessment and access to services.*

*Whole of life support – one assessment then reviews; Perhaps a 'once only' eligibility assessment, then 'reviews' at times of change.*

*Right of access to services should be an entitlement for everyone*

*Lots of talk about access – hearing impairment and intellectual disability have a double barrier which prevents access to many (nearly all) services due to communication issues. Can these be addressed?*

*What about people who don't identify as having a disability but still access and need support.*

*Very interested in further conversation about what will an NDIS mean for the 22% who don't receive funding.*

**Wrap around service provision is needed across the mainstream and disability sectors, to ensure flexible, individualised and innovative responses.**

*Homelessness issue is massive; How does NDIS link with mainstream service in other sectors e.g. mental health, homelessness, child safety. NDIS and Homeless? NDIS and Mental Illness (cyclical)?*

*Need transformation of how society responds to disability issues e.g. mainstream service provision.*

*Access needs to include education and inclusion provided across the community. Access for individuals/Families from birth throughout life that the whole community knows and embraces.*

*As service providers we spend a lot of time upskilling mainstream services on how to best work with clients with an Intellectual Disability. How would people with ID gain the best outcomes from mainstream services?*

*Emergency funding for homes/help etc should be available to all not just a few.*

**Marginalised groups with complex needs: what happens if there is no diagnosis?**

*What happens then? Jail? Mental health wards? That's what happens now. How do people get the most appropriate support if assessment tools are too narrow?*

*NDIS after the Child Safety experience - out of Child Safety - to where?*

*How do people under the NDIS step in and out of support?*

**How will the NDIS improve access and support from mainstream services?**

**Mainstream services already struggle to respond appropriately to people with an Intellectual Disability.**

*We need a combination of both the following mechanisms available to our agency where appropriate and available to support our capacity to deliver effective and appropriate service to Tier Two clients with intellectual, mental or physical disabilities. Advisory, training and resourcing specialist services to provide training, information and resources to support our capacity to effectively service Tier Two clients, and/or specialist services available to provide targeted practical support to Tier Two clients accessing services.*

*NDIS assessments need to complement assessment processes with other service systems. What if: we had an NDIS which was accessible in the same way as Medicare.*

**How do we create a culture shift within the employment sector which allows people with an ID to have a worthwhile shot at getting and keeping some work?**

*Concern about equating a quality of life with funding - people can be well funded to have an impoverished life?*

*Need to promote positive notion of 'citizenship'. Tangible contribution needs to be considered when receiving funding.*

*Different models of supported employment – Disability Employment Agencies and the proliferation of training courses has only been marginally successful. Only need to look at the unemployment statistics for people with intellectual disabilities to see that.*

### **Topic 3: Models for self-management of funding**

#### **How will self-management of funding work?**

*Would have liked some information regarding the 'how' of the model or more detail regarding the model itself*

*We need to unpack what self-managed funding means, the multiple ways it can be delivered.*

*Why do we need to have both brokerage and a Local Area Coordinator? Why not a Local Area Coordinator?*

#### **Self-management of funding will increase autonomy for people with an intellectual disability, but they will need support – how can this support be provided?**

*We need to acknowledge that they will need support simply to manage the maze of options and regulation they will encounter trying to locate service providers etc. Some will not have the informal supports to do this.*

*NDIS will give clients a voice, important that we work out how to make voices of people with ID more prominent*

*Videos demonstrated very strongly importance of need for independence - although acknowledgement of need for initial support to understand systems*

*Self-management is an excellent idea but how can people be supported to do this? Not everyone has a well resourced family to support them*

*How do we support a somewhat disempowered group of people to be able to take a leading, advocating role in their services? Who will assist the person with choices if there are no family members involved in the life or don't want to be involved?*

*Interesting to hear about the large numbers of people who have no families and advocates in their lives. Will be challenging to work out how these people would be able to manage their own funds especially if they are living very marginalised lives. Who will make the decision about how to manage their funding? Many of these people would need someone working closely with them to improve their life and their capacity to manage their own life.*

#### **Capacity building for people with an intellectual disability is critical to make self-management genuine**

*The discussion about decision-making is important. Absolutely necessary/vital to include the voices of people with ID. Also vital to provide the necessary supports/coordination so that this is meaningful (and not damaging to vulnerable people)*

*People who have been through the system (is older than 35) have had people controlling their lives for many years, have no experience in self-directions. How will*

*they be assisted to self-manage funding when there is no decision maker or someone who has limited vision for their family member?*

*Need a focus on how people with intellectual disability can become more informed consumers.*

***It is important to provide information about assessments and services in Easy English***

*Will the forms and funding guidelines be in a format that can be understood by people with an ID?*

*Financial responsibility documents should be short and sweet, and in easy English.*

***There is a need for independent self-advocacy organisations to support capacity building for people with an intellectual disability if they are going to self-manage***

*Need for opportunities for people with ID to have a say – an independent not service driven self-advocacy organisation*

*Good to see people with intellectual disability self managing their own funding and their views on this ... Shows that people do need advocates in their life to support them.*

***Families will also need capacity building***

*How do we assist families who have been knocked back time and time again to advocate become self directed decision makers?*