

NSW Council for Intellectual Disability

Submission to the Senate Enquiry into the National Disability Insurance Scheme Bill

Contacts

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About NSW CID

For over 50 years, New South Wales Council for Intellectual Disability has been the peak advocacy group in NSW for people with intellectual disability. We have a diverse membership of people with intellectual disability, family members, advocates, professionals and advocacy and service provider organisations. Our Board of Directors includes a majority of people with intellectual disability and we actively involve people with an intellectual disability in all aspects of decision making of our work.

The Council takes on such activities as providing policy advice, systemic advocacy, community education, and information provision and dissemination. NSW CID has an information service and resource centre providing information to people with intellectual disability, their families, carers, advocates and service providers.

NSW CID is committed to the principles of inclusion and participation and we aim to ensure people with intellectual disability are included in every aspect of the work we undertake.

This submission is in two parts

This submission is divided into two parts:

- 1. Issues for all people with intellectual disability pages 2.
- 2. Specific issues for people with intellectual disability on society's fringe page 9.

Endorsement of other submissions

We have read the draft submissions of:

Disability Advocacy Network of Australia National Council on Intellectual Disability Disability Network Forum NSW NSW Council of Social Service Australian Federation of Disability
Organisations
People with Disability Australia
First People's Disability Network
Aboriginal Disability Justice Campaign

We are in strong general agreement with those submissions.

Part 1 - ISSUES FOR ALL PEOPLE WITH INTELLECTUAL DISABILITY

Individual and Systemic Advocacy in the NDIS

"People probably don't have the support they need to speak up" 1

The place of advocacy historically has been central in assisting people with intellectual disability to get more choice and control over their lives. Choice and control remain key objectives for people with intellectual disability and are a present day challenge for the Australian community generally and the disability community specifically.

Facilitating people with intellectual disability to increased choice and control over their lives remains a challenge due to a complex array of community attitudes and values, legislation and social policy and practice that limits the enabling of people's civil, political, economic, social and cultural rights. The majority of the community are independent in their exercising of these rights. The majority of people with intellectual disability are, to varying degrees, reliant on others for the realisation of these rights.

Whilst the NDIS will deliver a fundamental change in the nature of the relationship between individuals with a disability, service providers and the community, people with a disability will still be reliant on the NDIS to provide the funding and the mechanism by which the funding is provided, in order for them to exercise their rights. People with intellectual disability have the right to, and need for, independent advocacy to enable them to overcome these barriers in order to exercise these rights in the context of the NDIS.

NSW CID believes that legislative effect should be given to the Productivity Commission's recommendation that "advocacy would make an important contribution to the effective functioning of the NDIS and to the overall effectiveness of the NDIS in delivering on its key objectives"²

"Sometimes when you have an ID you might not know how to ask, who to ask or where to ask or where to go about it, so it is hard"

Recommendations

 Consistent with the submission from the Disability Advocacy Network of Australia, the NDIS legislation should make provision for appropriate levels of funding to be allocated to the provision of independent advocacy support to people with an intellectual disability. This would require a new clause which allows for the 'Agency' to fund other agencies, independent of government.

¹ NSW Council for Intellectual Disability: Speak Out Reach Out Committee's Submission to the Productivity's Commission's Inquiry into Disability Care and Support

² Productivity Commissions Report

³ NSW Council for Intellectual Disability: Speak Out Reach Out Committee's Submission to the Productivity's Commission's Inquiry into Disability Care and Support

- 2. In the General Principles in section 4
 - a. Include the term "independent advocacy" in section 4(7) as one of the mechanism by which people will exercise the right to "pursue any grievance".
 - b. Extend section 4(9) by describing independent advocacy as one of the mechanisms by which people will be, "supported in all their dealing and communications with the Agency so that their capacity to exercise choice and control is maximised in a way that is appropriate to their circumstances and cultural needs."
 - c. Alternatively add: "People with disability should have access to independent advocacy whenever needed to assist the person to advance or protect their rights, including in relation to their participation in the NDIS"

Complaint, reviews and appeals

A significant problem with the current state based disability funding and service delivery model is the lack of adequate defined pathways for the resolution of disputes and conflicts. The lack of such pathways has created an 'us and them' mindset for stakeholders inclusive of the funding agency, the service provider, the person with the disability and families and advocates. This mindset is often not helpful to the resolution of issues. A defined process with an independent conciliator allows for people involved in the dispute and/or the conflict to be heard and for the development of confidence in resolving issues.

An informal process for the resolution of disputes and conflicts is always preferred before moving to more formal responses. Informality is a key characteristic for ensuring that any dispute or conflict resolution process is accessible for people with intellectual disability and their families and advocates. It ensures that a process of resolution remain inquisitorial rather than adversarial.

The experience of NSW CID is that people with intellectual disability will seldom make complaints independently and are likely to avoid conflict, especially with people or agencies they are dependent on. People with intellectual disability may often experience anxiety in relation to complaining or conflicts. Dynamics and experiences such as these, often inherent to the presentation of people with intellectual disability, are barriers to people getting more choice and control and the NDIS being able to improve their quality of life.

NSW CID is concerned that the NDIS legislation does not provide a general internal review process, complaints process or a process for resolution of disputes and conflicts between the 'Agency' and people with an intellectual disability. NSW CID understands that the 'Agency' being a Commonwealth agency will be subject to reviews by the Commonwealth Ombudsman – however, this would be a formal process and unlikely to cover many of the issues between a person with disability and the agency. Ensuring the opportunity of people with a disability to express their unhappiness with a process or a decisions, requires informality and approachability.

Specifically, NSW CID is concerned there is no informal process outlined in the legislation that provides for people with intellectual disability to complain or seek resolution to disputes and conflicts regarding the outcome of their assessments, plans and funding

arrangements. The statutory internal review mechanism in relation to specifically appealable decisions is inadequate in scope and form.

NSW CID expects that complaints / disputes and conflicts that involve a person with intellectual disability are most likely to be about the outcomes of assessments, the content of the plan and the funding of the plan. Whilst Part 6 – Review of Decisions describes what decisions by the CEO of the 'Agency' are reviewable, it does not describe the process for the review or who reviews the decision. Further Part 6 does not outline a process for the participation of people with a disability, their families and advocates in either the reviewable decision process or any more general complaints / dispute / conflict resolution process. Finally NSW CID believes that the 'review of a decision' is a formal process which may be a barrier to the participation of people with intellectual disability

NSW CID is also concerned about the use of the Administrative Appeals Tribunal as the final avenue for the resolution of disputes and / or conflicts

This concern is no reflection on the capacity of the AAT to engage in a review of decisions made by the 'Agency' rather, our concerns are in regard to the involvement and prohibitive expense of lawyers and the formality associated with many such appeals.

As well, such an action requires considerable investment in a long term process the outcome of which ensures there is a 'winner' and a loser to the resolution process. Rather the NDIS process for the resolution of disputes and / or conflicts needs to have a defined resolution process that is informal and seeks to avoid the outcome where there is a winner and a loser. Given that the dispute and / or conflict will often involve a person with a disability, the NDIS should avoid this outcome at all costs.

There are two other specific problems about the provisions for appeal to the AAT:

- The AAT legislation, unlike that for the general court system, makes no provision for another person to bring an appeal on behalf of a person who lacks the understanding to bring their own appeal.
- Unlike in relation to many other appeal rights to the AAT, the NDIS does not give an appeal right if the agency fails or refuses to make a relevant decision.

Similar issues in relation to disputes and conflicts between people with disability and their families and funded service providers or disability support organisations on the other hand.

Some states already have statutory complaints, review, monitoring and appeals bodies though they all have their limitations. In NSW, the Community Services (Complaints, Review and Monitoring) Act 1993 gives wide ranging roles to the Ombudsman complemented by a scheme of official community visitors and appeals to the Administrative Decisions Tribunal. In Victoria, there is a system including the Disability Commissioner and community visitors.

Recommendations

The review rights in the Bill should be rethought and expanded to include the following elements:

a. A general disputes/conflict resolution process within the agency based on inclusion of the person with disability, informality and conciliation.

- b. The Agency / CEO should be obliged to always provide reasons for decisions in relation to a participant.
- c. A statutory external and expert complaints and monitoring body.
- d. Appeals of reviewable decisions being ultimately determinable by a specialist, investigative and informal tribunal.
- e. Appeals being possible where the agency fails to make an appealable decision within a reasonable time.
- f. The Administrative Appeals Tribunal or other appeals tribunal needs legislative provisions to enable it to accept appeals made by a representative on behalf of a person who lacks the capacity to bring the appeal.

The NDIS as a Human Rights Instrument: Consistency with the UN Convention and the National Disability Strategy

Consistent with the submission from the Disability Advocacy Network of Australia, the NSW Council for Intellectual Disability believes that the NDIS should be situated in a human rights framework. This would require the NDIS to not only be consistent with Australia's obligations under the UN Convention of the Rights of Persons with Disabilities (CRPD), but should operate consistent with Australia's obligations under all domestic and international human rights law and treaties.

<u>Recommendation</u> - The word 'certain' in section 3(1)(h) of the Act should be replaced by the word 'all'.

Issues Regarding Capacity and Support for Decision Making

Articles 12 of the CRPD recognises that people with disabilities enjoy legal capacity on an equal basis with others in all aspects of their life and that Australia is obligated to support people to exercise their capacity.⁴

NSW CID acknowledges the soundness of the principles relating to plans in section 31. However NSW CID remains concerned that the practice of developing plans may not coincide with the principles.

The language in 33(1)(2) does not make it clear that the participant's statement of goals and aspirations is what informs the content of the plan rather than what the planner may think is in the person's best interests. Section 33(1) acknowledges that the plan must include a statement from the participant of their goals and aspirations but is not clear that this then determines the content of the plan.

Plainly speaking, NSW CID is concerned that the legal capacity of a person with intellectual disability should not be respected in practice when it comes to the development and implementation of a person's plan.

⁴ 2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.

^{3.} States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.

Article 12 (2)(3)(4) requires Australia to allow for a person to make decisions or, where their capacity is impaired, to support them in the making of decisions. Including people with intellectual disability in all aspects of the decision making process is a fundamental issue to the development of trust between the representatives of the Agency and people with an intellectual disability.

This then highlights the issue of who owns the plan?

- NSW CID believes that the plan should be owned by the participant and 'agreed to' by the CEO rather than 'approved'.
- NSW CID believes a change of language is needed in regards to the plans recognising that a participant's plan is an expression of who they are and what they want to be rather than a goal oriented service delivery plan developed by a worker.

<u>Recommendation</u> – Section 33 should require:

- a. a tighter nexus between the participant's statement of goals and aspirations and the contents of the participant's plan.
- b. the plan to be the participant's plan and agreed to, rather than approved by, the agency.

The Role of the Transition Agency

"I want to have a proper life...a better life"5

A strongly held criticism that NSW CID holds of the current state based disability service system relates to the inherent conflict between responsibility for acting as the primary funding agent for the disability sector and being a significant provider of a broad range of disability services. The inherent conflict develops when demand outstrips supply. NSW CID has observed that this tension leads to a rationed approach to the allocation of resources and impedes needs based access to services. Inevitably for a bureaucracy to manage the complex interaction between the life needs of a person living with a disability and a service system with finite resources, people with disabilities have lost choice and control.

Recommendation – There should be a clear separation in roles and responsibilities between that part of the NDIS that will be responsible for the management of the allocation of funding to a participant's plan and the part of the NDIS that will be responsible for the development and implementation of a participants plan.

Inevitably any system proposed will come with complexity and the issues arising as a result of its implementation will be played out as the system is applied to the lived experience of people with disabilities. NSW CID does believe however that this separation between funder and provider is important to retain the integrity the principles guiding action enunciated at the start of the legislation.

⁵ NSW Council for Intellectual Disability: Speak Out Reach Out Committee's Submission to the Productivity's Commission's Inquiry into Disability Care and Support

Managing Issues of Complexity

People with intellectual disability often present with a range of complex issues which can affect their ability to participate in office based issues. NSW CID wants to highlight the significant need for flexibility in the practice of working with people with intellectual disability with complex presentations around the assessment and planning process.

An example of the concerns held by NSW CID relates to the clash between the complexity of a person's life and the bureaucratic process as outlined in section 48 in relation to review and change of a participant's plan.

A person with intellectual disability may not be able to wait fourteen days for the CEO to decide whether to review the plan. Their needs may be immediate or the circumstances constitute an emergency such as homelessness, mental health breakdown, serious health issue or domestic violence. The person's ownership of their plan then requires an immediate response.

<u>Recommendation</u> – The process for review of a participant's plan should be required to operate as quickly as the needs of the participant dictate. This could include immediate interim variations to the plan to be followed by a more thorough review.

Indigenous Australians with intellectual disability

NSW CID remains concerned about access to all aspects of the disability service system for Indigenous Australians with a disability. This is particularly acute for Indigenous Australians who live in remote communities. Specific attention needs to be paid by the NDIS to address this issue.

Recommendations

- 1. The word "culture" should be included in section 3(1)(b), 4(2) and 4(11)(b) to make support of a person's culture a central element of the NDIS.
- 2. The nominee system should state a preference for a nominee of an Indigenous participant being a person from the participant's culture.

The agency's power to appoint a plan nominee

"When decisions are made for you – that's a big one"6

The slogan used by people with disabilities in the development of the United Nations Convention on the Rights of Persons with Disabilities was, "Nothing about us without us". This remains a key principle for the NSW CID. People with intellectual disability have told NSW CID repeatedly that they want more choice and more control over their lives. This request needs to be heard and respected even if people are uncomfortable about it implications.

⁶ NSW Council for Intellectual Disability: Speak Out Reach Out Committee's Submission to the Productivity's Commission's Inquiry into Disability Care and Support

The CRPD requires us to assume the competence and capacity of a person with a disability and that the onus of proof for incapacity lies with the applicant not the person with a disability.

Sections 86 & 88 give the agency very broad powers to take away the decision making rights of people with disability and in relation to whom to appoint as nominee. This is simply an administrative process. There is a safeguard in the review rights though only a person "directly affected" may exercise these rights. The person with disability would often lack the understanding, confidence and support to pursue review rights.

By contrast, appointment of a guardian under State/Territory legislation requires a tribunal hearing and specific evidence and findings about the person's lack of capacity to make relevant decisions, need for a guardian and about who is suitable for the role of guardian. Guardianship tribunals often have to deal with complex issues about whether a person does or does not have capacity for relevant decisions and about who should be guardian in the face of conflict within families or between families and service providers.

The current section 88 could lead to the absurd result that an administrative decision by the agency would prevail over the much more rigorous decision-making process of a quasi judicial tribunal.

Recommendation - Amendments should be made to include the following requirements:

- 1. If a guardian has been appointed with authority to make decisions about services, then that person should automatically be recognised as nominee. Similarly, if there is a nominee and a different person is appointed as guardian, the guardian should automatically take over as nominee.
- 2. If there is no guardian,
 - a. The agency should only be allowed to appoint a nominee if there is clear evidence that the individual lacks capacity to make decisions in relation to their plan and that supported decision making is not an adequate response to the person's decision making needs. (The requirement in section 88(3) is too weak.)
 - b. The agency should be required to be satisfied that the person appointed as nominee is willing and able to comply with section 80 and section 5.
 - c. An employee of the agency or a participant's service provider should be ineligible to be nominee.
- 3. The Act should require the nominee and the Agency to form and implement a plan to develop the participant's capacity to make their own decisions.
- 4. All appointments of nominees should be periodically reviewed.
- 5. The nominee system rules will also need to take account that many people with intellectual disability (especially those living isolated and at risk lives on society's fringe) will not have any family member or informal supporter who is willing and able to act as a nominee.

The agency's power to suspend a nominee

Section 91 says that the agency may suspend a nominee where there are "reasonable grounds to believe" that the nominee is likely to cause "severe" harm to the person. This is too high an onus of proof given the vulnerability of many people with disability and the impediments to them speaking out about abuse.

Recommendations

- 1. In section 91,
 - a. The word "believe" should be replaced by the word "suspect".
 - b. The word "severe" should be replaced by the word "serious".
- 2. There also needs to be a general capacity for the agency to reconsider the need for a nominee and who the nominee should be on request from the person with disability or another concerned person or the agency's own initiative.

Part 2 - SPECIFIC ISSUES FOR PEOPLE WITH INTELLECTUAL DISABILITY LIVING ON SOCIETY'S FRINGE

The danger of fundamental inequity in the NDIS

Many people with disability and their families will be aware of the NDIS, proactive in seeking support from it and have a very good idea of the kind of support that the person needs.

However, this is unlikely to be the case for many people with intellectual disability who live isolated lives on society's fringe and:

- In contact with the juvenile and criminal justice systems
- Leading superficially independent but at risk lifestyles
- Parenting children or
- Also having a mental disorder.

Unless the design and implementation of the NDIS includes accommodation of the needs of people on society's fringe, a fundamental inequity will develop. People who understand the NDIS and pursue support under it will obtain appropriate support. People who do not understand the NDIS and how it can assist them will continue to miss out as they often do in the current inadequate service structures.

The amendments to the Bill recommended below are needed to avoid this fundamental inequity. The proposed amendments are based on factors including:

- The need for an active process of engagement with people on the fringe to assist them to understand their needs and how the NDIS can assist them the first reaction of many people on the fringe will be, "Don't interfere in my life. I don't need help!" Active engagement is needed to address this.
- The importance of advocacy support for people on the fringe. Advocacy groups are often the only agencies who are trusted by people on the fringe.
- The often chaotic and fast changing circumstances of people on the fringe.
- The partnership often required between disability and health workers if the health needs of a person on the fringe are to be met. The same applies with other mainstream services.

- Many minors on the fringe not having a person with parental responsibility who is willing and able to act for the child or young person.
- The need to ensure that the disability requirement in section 24 does not inadvertently exclude people who have IQs from 70 to 85 and/or autism spectrum disorder (and substantially reduced functional capacity).

The following case studies illustrate these issues:

Michael - out of squalor and neglect

Michael grew up in an institution away from his family. His sister then helped him to move into his own place, but later she died. Michael refused offers of disability services saying he was independent now. 10 years later, the public housing authority found Michael living in squalor, obese and depressed.

A disability service spends a lengthy period getting to know Michael and getting his trust. Gradually, the service persuades him to accept help in his home, and to have a full health review and grief counseling. Michael now is healthier and happier than he has been since his sister died.

Natasha's anxiety leads towards gaol

Natasha's anxiety and limited problem solving and communication skills regularly lead to altercations with neighbours. The police come and she reacts in a hostile way to their authoritarian manner. An advocacy service helps Natasha with her police charges but she has been adamant she does not want other services.

Threatened with gaol, Natasha grudgingly agrees to services but it takes a long time for the caseworker to get her trust. Eventually, she agrees to see a psychiatrist and a behaviour support practitioner. They provide treatment and support for her anxiety and how to improve her interactions with the neighbours and police. A vital component is having a disability worker available after hours for Natasha to ring when she is anxious. The worker is usually able to talk Natasha through the situation.

Jenny – very vulnerable with an intellectual disability and mental illness

Jenny had an abusive childhood with her father. As a young teenager, she got into patterns of illicit drugs, casual sex and homelessness. She stole to support her drug problem and was in and out of court. Juvenile Justice linked her to a disability service but it found it very hard to locate her. She was then diagnosed with schizophrenia and it was difficult to establish a treatment regime.

Now, Jenny lives with her caring mother who also has schizophrenia and limited insight into Jenny's needs. Jenny remains very vulnerable to sexual and financial exploitation and in her drug use. She has poor time skills and seldom keeps appointments.

The disability service now tries again to engage with Jenny and slowly gains her trust. The case worker, Meredith, helps Jenny with regular personal crises. They develop a budget

together and Meredith helps Jenny implement it. Meredith manages to find suitable sexuality and drug counsellors. She takes Jenny to appointments with the counsellors, aids communication in the sessions and reinforces with Jenny what has come out of the sessions. Meredith takes a similar role with the psychiatrist. Slowly, Jenny decides she wants to change her lifestyle.

The need to ensure that people with intellectual disability living on society's fringe are included in the NDIS has become an issue of broad community concern. See our position statement and the list of eminent endorsers at page 14.

ACCOMMODATING PEOPLE ON THE FRINGE - RECOMMENDED AMENDMENTS TO THE BILL

1. Section 3 – Object of the Act

Add an object – "Ensure equitable access to the NDIS for all people with disability including those whose access may be impeded by lack of awareness of the scheme and of the potential benefits of being a participant in the scheme."

2. Section 4 – General principles

Add a principle – "People with disability should be supported to become aware of the NDIS and of the potential benefits of being participants in the scheme."

3. Chapter 2 – Assistance for people with disability

Add a section – "The agency shall seek to ensure equitable access to the NDIS, in particular by an active process of engagement with people with disability who are unlikely to be aware of the scheme or to understand the potential benefits of being a participant in the scheme."

4. Section 14 – Agency may provide funding to persons or entities

So as to cover crisis funding insert a new subsection (b) – "for the purpose of meeting the immediate needs of a person with disability pending the person becoming a participant in the NDIS and the development of a participant's plan."

5. Section 18 – Person may make a request to become a participant

As worded, only the individual with disability can make this request. This needs to be amended to at least allow a nominee to make the request.

6. Section 29 - When a person ceases to be a participant

As worded, a person ceases to be a participant as soon as he or she notifies the agency in writing that he or she no longer wishes to be a participant. Many people on the fringe fluctuate in their attitude to disability support. There needs to be a cooling off period and an obligation on the agency to explore the situation with the person and, where appropriate, appoint a nominee.

7. Section 33 and following – Participant's plan

For many people on the fringe, their goals and aspirations and reasonable and necessary supports will fluctuate often and quickly. Plans and the capacity to

review them need to accommodate these factors.

8. Section 33(6) – Where individual funding is managed by the agency, supports can only be purchased from registered providers.

This provision should be deleted. It will not take account of the varied needs of many people on the fringe, eg people in Indigenous communities where there may be no registered provider. People on the fringe may well be particularly reliant on the agency as the only available funds manager.

Section 34 (f) – Exclusion from "reasonable and necessary supports" of services
offered as part of a universal service obligation or in accordance with reasonable
adjustments

Superficially this exclusion is reasonable but it needs to take account of the very inadequate degree to which appropriate services are currently provided to people with disability in this way. For example, people on the fringe face great impediments to access any or appropriate drug and alcohol services. The mainstream service often needs to be complemented by a disability support worker who assists the person to access the service, assists communication between the mainstream worker and the person, assists the mainstream worker to make reasonable adjustments, and then goes away with the person and support them to act on the advice they have received. Rules or guidelines in relation to implementation of section 34(f) need to take account of these factors.

10. Section 74(1) (b) – The agency may determine that someone other than a person with parental responsibility can act for a child (up to 18 years)
Rules in relation to this need to take account of the needs of many children and young people on the fringe who do not have a person with parental responsibility who is willing and able to act for the child or young person.

Section 24 – Disability requirements

The first requirement in section 24(1)(a) is that a person has

a disability that is attributable to one or more intellectual, cognitive, neurological, sensory or physical impairments or to one or more impairments attributable to a psychiatric condition.

We are concerned to ensure that the Act does not inadvertently exclude many people living on the fringe who have IQs between about 70 and 85 (historically called borderline intellectual functioning), provided of course they have substantially reduced functional capacity. We see these people as having an intellectual impairment, or perhaps more strictly a cognitive impairment, consistent with the DSM IV definition of "mental retardation" and the Australian Government's approach to eligibility for disability support pensions. The methodology used by the Productivity Commission included these people within the costing for the proposed NDIS.

The NSW Law Reform Commission has recently considered the issue of a definition of "cognitive impairment" that would provide for special consideration in relation to issues

such as bail, sentencing and dismissal of charges without conviction. The Commission accepted the need to have a detailed definition of cognitive impairment so as to avoid doubt in relation to what it entailed. The Commission recommended the following definition:

- (a) Cognitive impairment is an ongoing impairment in comprehension, reason, adaptive functioning, judgement, learning or memory that is the result of any damage to, dysfunction, developmental delay, or deterioration of the brain or mind.
- (b) Such cognitive impairment may arise from, but is not limited to, the following:
 - (i) intellectual disability
 - (ii) borderline intellectual functioning
 - (iii) dementias
 - (iv) acquired brain injury
 - (v) drug or alcohol related brain damage
 - (vi) autism spectrum disorders.

NSW Law Reform Commission, Report 135, *People with cognitive and mental health impairments in the criminal justice system - Diversion*, sections 5.74 - 5.83 and 5.121-5.128. Further, many people on the fringe have a combination of IQs between 70 and 85 plus autism spectrum disorder and/or a psychiatric condition. The combination of these conditions can lead to very marked reductions in functional capacity. There are two possible problems here. First, it needs to be made clear that autism spectrum disorder is covered by the expression cognitive impairment. The NSW Law Reform Commission recommendation does that.

Second, on a literal reading, "a disability that is attributable to one or more intellectual, cognitive, neurological, sensory or physical impairments <u>or to</u> one or more impairments attributable to a psychiatric condition" would exclude a disability that only arises from the interplay of a psychiatric <u>and</u> another impairment. The same problem arises in the wording of the reduced functioning requirement in section 24(1)(c).

From our discussions with senior officers in FAHCSIA and the NDIS Transition Agency, we understand that the intention is to cover all of the above groups in the disability requirement. However, to avoid possible argument at a later time, it would be sensible to put this beyond doubt in the legislation.

Recommendations

- 1. The Bill should specifically confirm that the disability requirement in section 24 is met by a person with an IQ between 70 and 85 or autism spectrum disorder, provided the person has substantially reduced functional capacity. This could be done in a definition of "intellectual impairment" and/or "cognitive impairment".
- The wording of section 24(1)(a) and (c) should be clarified to make clear that a
 relevant disability and reduced functioning can arise from a combination of a
 psychiatric/psychosocial impairment and another impairment.



Position Statement:

The NDIS and People with Intellectual Disability who Live on Society's Fringe

The design of the National Disability Insurance Scheme needs to carefully consider the circumstances of all people with disability.

It would be easy to overlook people who lack self advocacy skills, family advocates and existing links with the disability service system. This is the case for a large number of people with intellectual disability who:

- Come into contact with the criminal justice system
- Lead superficially independent but at risk lifestyles
- Are parents, or
- Also have a mental disorder.

Many people have multiple of these characteristics.

People in these groups tend to live on society's fringe and often:

- Have histories of abuse and neglect
- Lack informal networks of support
- Are socially isolated and distrustful of service agencies
- Have very high support needs in relation to key life activities like decision making, control of their behaviour, dealing with personal crises, healthy lifestyles, avoiding personal and financial exploitation, dealing with the criminal justice system and caring for children.

Many people on society's fringe will need a funded package of support under the NDIS.

NSW CID calls upon the government authorities designing and implementing the NDIS to ensure equitable access to the NDIS by people with intellectual disability who live on society's fringe.

This requires that the NDIS includes:

- 1. An active process of engagement with individuals on the fringe so as to gain their trust and understanding of the benefit of support services.
- 2. Individual assessment and planning systems that accommodate the complex and dynamic needs of people on the fringe.
- **3.** Flexibility in the kinds of supports that can be funded to accommodate the disparate supports needed by people on the fringe.
- **4.** A robust workforce development strategy.

This position has been endorsed by:

Brendan O'Reilly AM

Former Director General, NSW Departments of Premier & Cabinet,

& Ageing, Disability & Home Care

Richard Bruggemann

Former CEO, Intellectual Disability Services Council, SA;

Professorial Fellow in Disability Studies

John Walsh AM

Partner Price Waterhouse Coopers; Associate Commissioner on the Productivity Commission Inquiry into Disability Care & Support

Robert Strike

Formerly President, Self Advocacy Sydney & Chairperson, NSW Council for Intellectual Disability;

Lifelong Achievement Award, National Disability Awards 2009

Fiona Stanley AC

Founding Director, Telethon Institute for Child Health Research, Australian of the Year 2003

Patrick McGorry AO

Psychiatrist

Australian of the Year 2010

Sir Gustav Nossal AC

Scientist

Australian of the Year 2000

Gwynnyth Llewellyn

Professor, Family and Disability Studies; Director, Centre for Disability Research & Policy; former Dean Of Health Sciences, University Of Sydney

Jeanette Moss AM

Parent advocate

David Richmond AO

Formerly Coordinator General NSW, Director General of NSW Health & the Olympic Coordination Authority;

Author of the 1983 Richmond Report

Terry Carney

Emeritus Professor of Law, University of Sydney; Past President, International Academy of Law and Mental Health

Children with Disability Australia

Disability Advocacy Network Australia

National Council on Intellectual Disability

National Ethnic Disability Alliance

Royal Australian and New Zealand College of Psychiatrists

Women With Disabilities Australia (WWDA)

Kevin Cocks AM

Anti-Discrimination Commissioner Qld; Human Rights Medallist

The Hon Alastair Nicholson AO RFD QC

Former Chief Justice, Family Court of Australia; Chair, Children's Rights International

The Hon Paul Stein AM QC

Former President of the NSW Anti Discrimination Board; Chair of the NSW Law and Justice Foundation

Richard Matthews AM

Former Deputy Director General, NSW Health & CEO, Justice Health

Michael McDaniel

Professor, University of Technology Sydney; former Dean of Indigenous Education, University of Western Sydney

Stella Young

Disability activist and journalist

Nick Lennox

Director, Queensland Centre for Intellectual & Developmental Disability; President, Australian Association of Developmental Disability Medicine

Jane Fraser AM

Parent advocate

Eileen Baldry

Professor of Criminology;

Deputy Dean of Arts and Social Sciences UNSW

Mark Ierace SC

Senior Public Defender NSW

Errol Cocks

Professor of Disability Research, Curtin University of Technology

Colleen Pearce

Public Advocate Victoria

John Brayley

Public Advocate South Australia

Graeme Smith

Public Guardian NSW

Kevin Martin

Adult Guardian Queensland

Jodie Cook

Public Advocate Queensland

Anita Phillips

Public Advocate ACT

Wayne Bennett OAM

Rugby League coach

Chris Cunneen

Professor & Leader in Justice & Social Inclusion, James Cook University

Eric Emerson

Professor of Disability & Health Research, Lancaster University, UK; Professor of Disability Population Health, University of Sydney

Robin Banks

Anti-Discrimination Commissioner Tasmania

As at 13 January 2013

"Those on the fringe must never be left behind."

Tim Fischer AC