NCID

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national council on
intellectual disability

It’s my life … I’ll do it my way (part 2)

Submission to the
Long Term Disability Support
Productivity Commission Inquiry Draft Report 2011

Version 2.0

18 May 2011

The National Council on Intellectual Disability (NCID) was established over 50 years ago by parents and friends, in an endeavour to improve the quality of life of people with intellectual disability and to fill the need for national unity and information.

The Council is the recognised national peak body with the single focus on intellectual disability, ie, our actions and priorities centre on issues that affect the lives of people with intellectual disability and their families. Our mission is to work to make the Australian community one in which people with intellectual disability are involved and accepted as equal participating members.

NCID has over 5,000 members representing all 8 States and Territories. In addition to having people with disabilities on its Board, NCID receives policy advice from Our Voice. Our Voice is a committee the membership of which is exclusively people with intellectual disability representing all States and Territories.

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Statement of Principles

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

National Council on Intellectual Disability will:

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

Consultation Statement

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

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

On the issue of our response to the Productivity Commission's draft report on Long Term Support for People with disabilities National Council on Intellectual Disability has:

- ✓ held forums with members
- ✓ held a forum for people with intellectual disability and families (Having a Say Conference)
- ✓ held specific discussions on the issues of;
  - ➡ employment

- education
- community capacity building
- capacity building for people with disabilities and families
- Commonwealth/State cooperation
- advocacy
- sponsored an international expert on employment and community living
- supported people with intellectual disability to attend relevant conferences and to prepare submissions

National Council on Intellectual Disability endorses the following submissions to the Productivity Commission Inquiry into Long Term Support for People with Disabilities:

Speak Out Reach Out (SORO)
Disability Advocacy Network of Australia (DANA)
NSW Council on Intellectual Disability (NSW CID)
South Australia Council on Intellectual Disability (SA CID)
Human Rights Analysis - proposed National Disability Insurance Scheme

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Introduction

It is very pleasing to see in this report, an acknowledgement of the unmet need, the fragmented system and the difficulties faced by people with disabilities on a daily basis for many years. The report is quite comprehensive and shows that an effort has been made to understand the real situation of people with disabilities in Australia.

In particular, we commend the report for the following aspects;

- recognition of people with intellectual disability as a group that has need of ongoing support;
- recognition of the need for personalised and individualised support as the best way to meet the needs of people with disabilities;
- recognition of the need for people with disabilities and their families to be in control of funding and decision-making in regards to disability support, particularly the ability to cash out funding packages;
- recognition of the need for a legislated formula and quarantine in funds to be used for disability support that comes from General Revenue.
- recognition of the need for broad community awareness and capacity building.

We do, however, have some specific concerns about some of the structure recommended, the principals, and detail of how outcomes of the scheme are defined and its potential impact on people with intellectual disability.

Key Issues

People with intellectual Disability

NCID is strongly supportive of Intellectual Disability being maintained as an eligibility criterion in the National Disability Insurance Scheme (NDIS).

For over 10 years NCID, our Agency Members and the intellectual disability community have demonstrated through a strong evidence base that ALL people with intellectual disability have complex and significant support needs.

The American Association on Intellectual and Developmental Disabilities (AAIDD), an international authority on this subject, states:

> "Providing supports to people with intellectual disability enables their functioning in typical life activities in mainstream settings but does not eliminate the possibility that they will continue to need ongoing supports. Put another way, if supports were removed, people with intellectual disability would not be able to function as successfully in typical activities and settings."

We believe the failure to recognise this evidence will inevitably lead to significant disadvantage for people with intellectual disability.

See attachment 1.

Advocacy

National Council on Intellectual Disability endorses the submission by the Disability Advocacy Network of Australia (DANA). The need for the funding and provision of effective advocacy was the major omission from the Productivity Commission's draft report and the adoption of the recommendations in the DANA submission will address this.

In particular NCID would like to highlight the following statements in DANA's submission:

"The benefits of self advocacy training are often only apparent and recognised after training is complete and participants usually need considerable but hard to quantify ongoing direct advocacy support to benefit from it."

"An identifiable, justifiable proportion of the total NDIS bucket of funding should be provided to an independently constituted statutory advocacy authority to administer and distribute to independent advocacy organisations so as to ensure that the strength and effectiveness of advocacy is assured and that the advocacy provided remains focused wholly on the rights, interests and well-being of the person with disability."

Community Development

Although the Productivity Commission in its draft report talks about community awareness as a role under Tier 2, there is little mention of community development.

In the context of people with disabilities, community development must be about access and inclusion in all parts of the community from the beginning. This means building the capacity of the community and of people with disabilities and their families, and engaging with the community. In practice this type of work is often carried out by State and Territory Governments and local councils. Some do a very good job of community development specifically including people with disabilities and their families by ensuring there is expertise within the council to inform the different areas in which the council works. Others seem to miss people with disabilities and their families from much of their community development efforts, although they may have some very good community development initiatives.

Our experience has been that often an initiative to include people with disabilities touches on many of the same issues for inclusion for everyone in a community. This can mean that community development projects to increase the inclusion of people with disabilities end up being broadened to improve access for all people. This can be a very good thing if a social inclusion perspective is initiated at the start of any project. The problem that often occurs is that over time minority groups and disadvantaged groups, like people with disabilities, become lost in the broader policy that is about inclusion for all, because there is no expectation of the need for expertise in these specific areas. Also, because the adjustments and individual responses often needed become forgotten without a constant reminder from someone with expertise.

Our concern in relation to the Productivity Commission draft report and the NDIS is that funding is required to ensure social inclusion. Community development must include and build the expertise in community of people with disabilities and this requires resources. We agree that mainstream services such as those provided by States, Territories and local government authorities must include people with disabilities and their families as a matter of course and this is legislated under the Disability Discrimination Act. However, it is ensuring that there is expertise on disability within the mainstream organisations as well as expertise within the disability sector of mainstream issues that requires specific funding.

There is an excellent example in Victoria of placing disability community development expertise within local government specifically to address this issue. This is the Metro Access and Rural Access initiatives. Also, New South Wales Council on Intellectual Disability (NSW CID) has done specific research on the need for disability expertise within the health system to ensure the inclusion of the needs of people with disabilities in relation to access to health services.

A key component of community development and social inclusion is engagement with the community. Engaging with people with disabilities in a meaningful way requires more time and resources than if the same was done with people without disability. It is essential that engaging properly with people with disabilities and their families as part of community development and social inclusion at a broad level, as well as relating to disability specific policy and programmes, is funded appropriately.

See the section below on national v/s regional responses for our detailed comments on funding.

National v/s Regional responses

NCID and its member organisations have grave concerns over the need for a national agency which holds the funds, employs the staff and makes decisions around funding allocation for innovation, capacity building and community development that has been put forward by the Productivity Commission in its draft report.

A centralised decision-making authority can stifle innovation and creativity at local levels, as with distance can come a lack of understanding of local circumstances and conditions.

It is extremely difficult for there to be a relationship with funding bodies when the decision makers are geographically distant. People and organisations in the north of Western Australia and Queensland have developed relationships with State bodies over many years that are still tenuous due to distance.

National Council on Intellectual Disability recommends that the Productivity Commission look at mechanisms for State, Territory and local authorities to have direct control over funding for these activities.

The concept of subsidiarity, decision being made as close to the person(s) affected by the decision, is an important one within a democratic state. It ensures that decisions are made in the best interests of those affected and not by distant 'bureaucrats'.

Previous experience with Centrelink and FaHCSIA has shown that regional offices will refer anything that is outside guidelines to head office which means there is very limited ability for quick responses and, again, the knowledge in the head office does not reflect the local conditions.

NCID believes a federated model with State and regional councils in control of local coordination/case management and allocation of funds to organisations for capacity building and community development would provide greater responsiveness and flexibility. And, the innovation that is often needed in rural and remote areas to overcome barriers would not be stifled by a lack of understanding or lack of relationship at the local level.

This does not mean that there should not be a central independent agency that holds the pool of funding which is collected through legislated formula to provide the long term funding. Having the funding legislated to be in one fund for all Australians provides a certainty of funding in the long term for people with disabilities and their families which cannot be realised when there are multiple sources of funding. The central agency could then be used for broad national community awareness campaigns, monitoring of consistency in systems, and data for research and trends.

Funds for capacity building, community development and innovation should be allocated on the basis of the number of people in the State or Territory who are in receipt of funds from the NDIA. The States and Territories should have complete control over the expenditure of those funds with the broad parameters being established through the National Disability Strategy.

Key Points

- The National Disability Insurance Scheme (NDIS) must be directed by the United Nations Convention on the Rights of people with disabilities (UNCRPD) in its values, principles, structure and implementation.
- It is vital that everyone in the proposed National Disability Insurance Agency (NDIA) and associated organisations demonstrate a positive attitude towards people with intellectual disability.
- Outcomes must be evidence-based, and not distorted in implementation by the agenda of government and service providers.
- People with disabilities, including people with intellectual disability must be actively involved in the identification and development of outcomes.
- People with disabilities must play an active role in the development and design of community awareness campaigns.
- Disability expertise must be established in mainstream health, mental health, justice, ageing and other human service areas.
- Support for people with complex needs must be in place.
- There must be a flexible approach to what can be funded – not a prescriptive list.
- There should be no means testing and no co-contributions.

- People with intellectual disability must be supported to find real jobs with decent wages as per Article 27 of the UNCRPD.
- There must be expectations that people with intellectual disability can work.
- Support for all people with intellectual disability to be able to undertake job readiness training, find a job, maintain a job and be supported on the job must be funded.
- People with intellectual disability should be able to live in the community with whom they want and have a choice of housing options that will lead to good lives. The support needed to live in the community (domestic, socialisation, personal care, community access, etc.) should be attached to the person who requires the support and therefore be portable and separate to the provision of bricks and mortar as per Article 19 of the UNCRPD.
- Individual aids and equipment for work or education should be attached to the person for whom it is needed.
- Assessment for eligibility must be simple and consistent, and done locally – with the choice of completing a self-assessment using a process based on the In Control assessment adopted by local authorities in the UK.
- The NDIS must put in strategies to support the cultural change needed to move to person-centred approaches and systems.
- Planning for supports and funding needed must be done locally, involve people who know the person and adequate time must be built into the process to ensure the active involvement of all participants.
- People with disabilities and families need to be part of the development and implementation of any assessment tool and process.
- The opportunity to 'cash out' an individual package must be open to everyone and must include with extra supports, eg. training, brokers, mentors.
- There must be opportunity for training and capacity building for those who wish to move from using a service provider or broker to cashing out.
- People with disabilities, including people with intellectual disability, must be active participants on the Governance board of the NDIA and hold the majority on the Advisory Board. The NDIS is being developed to support people with disabilities, not service providers.
- The NDIS should assist in development of new ways of thinking and delivering services. It should not prop up failing service providers, particularly where people with disabilities can and are choosing alternatives.
- A person's individual data belongs to them and should be portable by them.
- No data mechanisms or data should be used to undermine the support people receive.
- There should be an independent Ombudsman for complaints and systemic review of issues; the Ombudsman must present an annual report to parliament.
- People with disabilities and their representative organisations must be actively involved in the development of implementation plans for the NDIS and NIIS.
- Trials should be held in every State.
- Evaluation should be ongoing with people with disabilities, including intellectual disability, actively involved in the evaluation, feedback and

development of improvements throughout the trials and implementation. Regular evaluation must take place.

- No person currently receiving services should be worse off.

Principles

The following key principles were developed by the National Council on Intellectual Disability (NCID) in their initial submission to the productivity commission.

National Council on Intellectual Disability

For the National Council on Intellectual Disability to support any National Disability Long-term Support Scheme the scheme must ...

1. Be an entitlement scheme which is enshrined in legislation for ALL people with intellectual disability
2. Be a funding scheme and not a model of service delivery
3. Meet the support needs of ALL people with intellectual disability
4. Meet ALL the support needs of people with intellectual disability over their lifetime
5. Ensure that people with intellectual disability and, where appropriate, their families, have direct control over the resources allocated to meet their specific support needs over their lifetime
6. Ensure people with intellectual disability have access to full social, economic and community inclusion and participation
7. Ensure there are no impediments, financial or otherwise, to people with intellectual disability gaining employment
8. Ensure that any adopted scheme is not bureaucratic or process driven

Adopted by NCID's Board on 18 December 2009

National Disability Strategy and UNCRPD

The National Disability Strategy released recently has adopted the principles set out in the UNCRPD Article 3:

- respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons
- non-discrimination
- full and effective participation and inclusion in society
- respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
- equality of opportunity
- accessibility
- equality between men and women
- respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

It is assumed that whatever scheme is adopted by government, it would fall under the National Disability Strategy in the same way the current National Disability Agreement does and would therefore be bound by these same principles. This scheme must also be one of the ways the UNCRPD is implemented in Australia. This needs to be clearly stated in the report.

The draft report does not identify principles specifically and, as such, there are instances of seeming contradiction, for example, the draft report recommends personalised and individualised planning through assessment, yet the draft report also suggests that the assessment be done by a person who does not know the person with a disability so cannot assist with planning in a comprehensive way. Also, there is discussion on people with disabilities being able to self-manage their funds, yet they cannot be part of the governance of the scheme which is in direct contravention of the UNCRPD Article 4, point 3 which states:

> In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organisations.

Clear principles that guide the scheme and connect it to the UNCRPD with economic and social outcomes that are evidence based should be the first point in this system.

Quite clearly, the initial basis of the NDIS is a way of pooling and quarantining the funds needed for disability support now and in the future, followed by allocation of funds in the most effective way to benefit those receiving the funds. Without some core principles to guide how this is done there is a risk of a mish-mash of market-driven approaches that may leave the most vulnerable without or with limited options.

In Control Australia

Groups such as In Control Australia have principles that are clearly about how services and funding are delivered and controlled:

Principles

1. Independent Living
I can get the support I need to be an independent citizen.

2. Individual Budget
I know how much money I can use for my support.

3. Self-Determination[1]
I have the authority, support or representation to make my own decisions.

4. Accessibility
I can understand the rules and systems and am able to get help easily.

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[1] The Five Principles of Self-Determination

Freedom: The right to make basic choices about your life.
Authority: To control the money that is spent on your behalf and the supports you receive.
Support: To develop your dream-to reach your goals.
Responsibility: To give back to your community and be accountable.
Confirmation: Affirming the central role you have in leadership and change.

5. Flexible Funding

I can use my money flexibly and creatively.

6. Accountability

I will tell people how I used my money and anything I've learnt.

7. Capacity

My capacity is assumed, and I can also get information and support to build my vision of what is possible in my life, and how that can be arranged and monitored.

In Control Australia 2009

UNCRPD

The following principles are in the report and need to be drawn out, stated clearly up front, and used to check that the whole scheme is value-based as well as economically sustainable. The references to the UNCRPD gives some specific examples of these principles, however many are inherent in the convention as a whole:

- Give people power and choice (Productivity Commission 2011, p25; UNCRPD Article 3a and 4.3)
- Keep the person with the disability front and centre (Productivity Commission 2011, p5.20; UNCRPD)
- Those in need are entitled to support (Productivity Commission 2011, p4.26, p7.31; UNCRPD Article 19 and 26)
- Funding is individually allocated (Productivity Commission 2011, p6.1, UNCRPD Article 3a and 4.3)
- Assessment, planning and supports are person-centred (Productivity Commission 2011, p5.1, p6.2)
- Supports promote social inclusion and citizenship (Productivity Commission 2011, p3.7, p8.2; UNCRPD Article 3c, 19 and 26)
- There is a sustainable, certain, stable funding base (Productivity Commission 2011, p12.1, UNCRPD Article 4)

Outcomes

The Productivity Commission puts great value on having a good evidence base for the policy and interventions to be used that can meet the outcomes. (Productivity Commission 2011, p10.2). NCID also believes that there must be good evidence that shows that outcomes can be met in order for resources to be applied to that policy or service. The bigger question here is what are the outcomes and who decides what the outcomes are? Chapter 10 of the draft report asks some of these questions but more from the perspective of costs and benefit.

Outcomes come right down to the assessment and planning stage, in that the person with the disability is putting in their plan, their desired outcomes. At a policy level, outcomes must also meet the expectations of people with disabilities. An example is the outcome of employment for people with disabilities. The expectation is that this will be sustainable for the person, will pay a decent wage, and will be in an environment that meets with all the work conditions that anyone would expect. Policy and practice should be then aimed at meeting that outcome. In the area of employment ,this outcome is often confused in its implementation with a government policy outcome of reducing numbers on the Disability Support Pension. There are also assumptions throughout the Draft Report that there are people who cannot work without defining who that might be, whereas evidence supports the expectation that people with intellectual disability can get real work and paid real wages in open employment.

The NDIS must be sure to engage people with disabilities where there is not already clear evidence on the outcomes that are most beneficial to people with disabilities. These outcomes must be in line with the UNCRPD. Some specific research on outcomes has been done by various State governments around their disability standards. However, there also needs to be analysis such as at the 2006 Roundtable on Intellectual Disability Policy, where presenters discussed research on defining and measuring outcomes (Erin Wilson) and the mismatch between stated visions and values and practice (Tim Clements). (Bigby and Mansell, 2006)

There is concern that the Draft Report focuses on cost effectiveness as the main outcome rather than what people with disabilities want and need, although we would argue that more often than not the best outcomes for people with disabilities are the most cost effective.

Chapter 3: Who is the NDIS for?

With regard to the recommendation of the three tiers of support (Recommendation 3.1).

Awareness Raising

Article 8 of the UNCRPD is about awareness-raising and lists specific measures whichinclude fostering respect for the rights of people with disabilities, combating stereotypes, and promoting the capabilities of people with disabilities (UNCRPD). If the NDIS is the vehicle to take on this role there is an expectation that it will fulfil this obligation, which includes programs about the contributions of people with disabilities to the labour market, and programs in the education system and media.

The Draft Report does discuss the promotion of people with disabilities, particularly in relation to employment and other strategies. These strategies should not be seen in isolation but be linked in to the work that is being done under the National Disability Strategy. More importantly, people with disabilities must, from the start, be a part of the development of these strategies and campaigns as there are many examples of patronising campaigns which show people with disabilities as objects of pity and charity. A case in point is the difference between the advertisement for the Cerebral Palsy Alliance (NSW) compared to the ad for the Cerebral Palsy League (QLD) and the consequent discussion on Ramp Up, 22 March 2011 which highlighted the opinion of people with disabilities about their portrayal in the media (Winther 2011). These were ads for fund-raising which one hopes will no longer be needed with the introduction of an NDIS. The very successful Bar None campaign in Victoria was successful because it had journalists initiating the change to their writing with ongoing input, monitoring and mentoring from two people with disabilities (Richardson 2009). Other States, such as NSW and WA, have developed Media guidelines and booklets; yet it is hard to say if this has made much difference by itself (NSW Disability Advisory Council 2011; Disability Services Commission WA 2011). Certainly those resources that have already been developed should not be discarded if found to be useful.

There is little research on the most effective ways of raising awareness and changing attitudes about disability, but the involvement of people with disabilities is paramount. People with intellectual disability are keen to be involved in campaigns, community education etc, and they are clear about their message and how they would like to be portrayed.

Information and Referral

The information and referral role of Tier 2 seems to be quite narrow. The report is unclear about where this role would be situated but there would certainly need to be offices or information points at the local level that were accessible. The detail of what is available at a local level is different in many areas and people who are local and know an area are more likely to be able to give more detailed and useful information than a person at a database in Canberra.

Information is not a static group of words on a computer or brochure. Being an information provider means sharing knowledge and having relationships with key community contacts and services – this is significantly more beneficial than a stand alone database. Also, having the opportunity to attend local events and interagency forums enhances the capacity of information services to be able to respond more effectively.

People with intellectual disability may not use computers or other technological means of finding information due to their difficulty or because of being unable to afford such items. Multiple sources of information are necessary with awareness campaigns about the information points. The New South Wales Council on Intellectual Disability (NSW CID) original submission to the Productivity Commission Inquiry detailed a range of ways people with intellectual disability can get information (NSW CID 2011a).

Rural and remote access to databases, information points and call centres needs to be considered as does the reality of time zones. In summer Western Australia is 3 hours behind the Eastern States and access to information must be available when people need it.

Supported referral and advocacy is often required where mainstream services do not want to provide the support or do not know how to provide the right support for people with disabilities. This is a much bigger role than the Commission has described – yet is often important and often done by advocacy agencies. A person with a disability may be quite articulate but, if mainstream services are reluctant to include someone, more than a letter referral is required. People with disabilities WA state in their 2009 Annual report that 23% of their advocacy support was support which linked people to options and provided general advice (PWDWA 2009).

Many advocacy agencies provide valuable training and information on how to support people with disabilities to health, housing and other services, as well as supporting individuals directly to use these services. People with disabilities Australia say they provided training to over 1,600 participants in NSW and Qld in 2010 (PWD 2010). The NSW CID has a range of presentations on health and has recently targeted the National Alcohol and Drug Agency (NSW CID 2011b) .

These elements are all needed for information and referral as much is about providing capacity building for people with disabilities to access mainstream services, and capacity building for mainstream services. Currently, these roles are done by a mixture of agencies including advocacy organisations.

There needs to be continued independent advocacy for people with disabilities outside of, and funded separately to, the information/referral and Disability Support Organisations discussed in the Draft Report.

Interface with Health, Mental Health, Ageing and Justice Systems
Memorandum of Understanding's (MOU's) at a high policy level does not necessarily mean that services will be provided or the issue understood at the level of the gatekeeper to the service. Some specific disability awareness and promotion strategies are also needed which educate front of line staff about disability support.

MOU's with other sectors that provide health, mental health and aged support need to not only be about people being referred but there needs to be a lot of work done on the interface between systems for people with complex needs who may cross over various systems. Many States already have specialist programs in place for people with complex needs who require multidisciplinary case management and these should continue and be expanded to cover the need. This is especially important where people with intellectual and cognitive impairment are in the justice system. For example, in Victoria is the Multiple and Complex Needs Initiative (Department of Human Services Victoria 2011), and WA has a People with Extremely Complex Needs project (Mental Health Commission WA 2011). Many states also have diversionary programs in the justice systems that work to differing degrees however there is still over representation of people with intellectual disability in the criminal justice system (Law Reform Commission of Western Australia 2009). These different interfaces must be taken into account.

MOU's should ensure that expertise in these other essential service systems (health, mental health, etc.) is developed to ensure that there are people who know about dual diagnosis issues (intellectual disability and mental health), depression in people with disabilities and carers, dementia with conditions like Down Syndrome and Multiple Sclerosis, to name some examples. These people often slip through the gap because neither system will take them.

An area like health is very complex, and access to the health system is often an ongoing part of the life of a person with a disability. The NSW CID has done research and consultation in this area that shows that a dedicated specialist resource is needed that understands, and has a knowledge base of intellectual disability and the associated health issues. This resource could inform and support mainstream services (NSW CID 2010).

The rights of people with disabilities to access and use services in their communities, and the value this provides to the community as a whole, must be the cornerstone of all approaches in Tier 1 and 2, as stated in the UNCRPD.

Eligibility for funding

Recommendation 3.2 details the eligibility criteria for Tier 3: funded support. We commend the report for inclusion of people with intellectual disability as automatically being eligible for support and for understanding that support for most vulnerable must be available.

The Draft Report acknowledges that those with 'mild' intellectual disability will be covered, yet the assessment process could leave this group at a distinct disadvantage. The Community Living Association have submitted a response to the Productivity Commission Draft Report which specifically highlights these issues (submission no . ....

Many people with disabilities have increased effect of ageing, because of disability, much younger than 65 and/or age-related conditions that develop eg: Down Syndrome and dementia, plus the specific needs relating to their disability (Neill 2007). People with disabilities are also living longer and healthier lives for the most part so there is a greater intersection with the aged care sector. The NSW CID put in a submission to the Productivity Commission Inquiry into Caring for Older Australians that addresses many of these issues. The Draft Report takes into account most of these issues. However, it does not seem to allow accessing both systems at the same time. As in recommendation 3.5, people should be able to migrate their funding to the aged care sector, but they should also be able to split their funding between sectors (via their plan) to purchase expertise.

We support recommendation 3.6. The NDIS should include all eligible people not just those new or currently unfunded as this would lead to two systems remaining for funding allocation. This transition needs to be very carefully done as many people currently receiving support would be fearful that they would get reduced support.

Chapter 4: What Individualised supports will the NDIS fund?

What can be funded must focus on the needs of the individual. The report acknowledges the fragmented and silo-based system currently in place.

There needs to be a certain amount of flexibility factored in to what can be funded. The concept of 'reasonable and necessary' with guidelines as described in the Draft Report are a way of keeping a measure of flexibility and this is far more preferable than a set list of what can be funded. Although the Commission and research done may be able to identify what the most common supports are that people need, there are those on the margins (people with borderline dual diagnosis, 'behavioural' issues, rare disabilities) who may need very diverse long term support. For example, a person with a mild intellectual disability and borderline personality disorder may need months of a very simple engagement like going to the movies regularly with the same person before being able to move on to receiving more social skill or independent living style support. Those with complex needs that may change quite rapidly need support options that can change with them. Research shows that a high percentage (up to 50%) of people with intellectual disability have a dual diagnosis (Prasher and Routhu 2003). How changes in use of funding is administered is extremely important in these cases and we would recommend that the local case manager should have some discretion to approve changes in consultation with the person with a disability and family.

Recommendations 4.2 and 4.3 are about no income tests but small up front contributions. The idea that this could be waived for families who have contributed to support costs means it will be waived for all people with families, but there are many people for whom an upfront contribution is simply not affordable. Many people with disabilities, including those with intellectual disability, are living on the poverty line and not reliant on family (National People with Disabilities and Carer Council 2009, section 2.3.6). This recommendation discriminates against those without family support. There should be no means testing and no co-contribution.

There is also concern that if the formula for the amount of funding is not correct, and the legislation not tight about these requirements regarding income tests and contributions, then we may see an erosion as has occurred with Medicare where 'gap' costs are increasing and 'bulkbilling' is limited.

Recommendation 4.4 says people should pay the full costs of services (primarily therapies), for which clinical evidence of benefits are insufficient or inconclusive, if they wish to consume those services. How might this be managed? If some things are covered by private health insurance, then shouldn't they be covered by this? How much clinical evidence is required and who makes the judgement call? This requires further clarification.

In recommendation 4.5, the Commission states explicitly that 'specialised employment services, disability-specific school to work programs, taxi subsidies, and specialised accommodation services should be funded and overseen by the NDIS'. These are all large areas where many service providers have a vested interest and will not necessarily want to change, even though evidence may show better ways of meeting outcomes.

Employment

We believe people with all types of disability can find and get a job in open employment with the right support[2]. The correct disability-specific support to maintain a job is what needs to be funded, with some dollars going to extra on the job training, equipment modifications, etc.

In the Draft Report, the Productivity Commission (2011, p1.2) restates its terms of reference and shows that its inquiry was to examine a support scheme that “provides for people to participate in education, training and employment where possible” as one of its objectives.

In Chapter 4, the Draft Report says that the NDIS will include "Specialist employment services — that provide or prepare people for jobs (including transition to work programs)." (Productivity Commission 2011, p4.4). Yet further on, it also says that "employment services should remain a mainstream concern" (Productivity Commission 2011, p4.12).

This response is clearly about support for Australian Disability Enterprises (ADE) which do not provide real wages for people with disabilities and do nothing to reduce the

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[2] Though small in number, people with profound severe and multiple disabilities which can include complex health needs, have the need for a very different type of support.

Being in employment cannot only be entirely inappropriate for someone who requires such intensive levels of “care”.

Such expectations could be quite detrimental to and interfere with the individual’s well-being due to their very fragile state of health.

This not only affects the particular person, due to their failure to meet the unattainable expectations of others; such a blanket expectation also has the propensity to create great strain on the family carer if they have to “pick up the pieces” at every failure to meet those expectations, regardless of the reason.

This does not mean there is then less requirement for these people to be supported to participate and be included in everyday life. It just means that they have to be assisted to have “different to employment” opportunities to do so.

dependence on the Disability Support Pension. These types of specialist employment support services have a history of grouping people with intellectual disability in segregated/congregated models of service, where people rarely move into open employment.

The Department of Education Employment and Workplace Relations (DEEWR) Disability Employment Services (DES) is a specialist disability program. It funds specialist disability employment services. Some of these are specialist intellectual disability employment services - including moderate intellectual disability. The DES program is what is currently in place to help people with disabilities with the most disadvantage to get support to work in a real job. This should be the focus of the NDIS support for employment.

What we know from the evidence is that successful open employment for people with intellectual disability is characterised by:

- a secondary education which builds employment goals, provides an awareness of what work is, offers work experience - from voluntary to paid work
- high expectation of obtaining work in open employment before leaving school
- being taught community-based skills, such as getting around the community with appropriate behaviour in typical settings including the workplace.
- a transition between school and open employment, whereby a specialist open employment service facilitates a smooth transition from school - maintaining the work goal of the student
- a service competent in the place and train model of employment assistance - finding a job, customising or creating a position where necessary, teaching job skills on-the-job to the standard required by the employer, and providing long term and ongoing support to the employee and employer.

Every young person with intellectual disability should receive the resources and expertise to pursue the above pathway to real work. This is something now offered to all people with intellectual disability in Washington State, USA where It is expected that you are either working or looking for work – and in the final years of school that you are getting ready through transition programs with employment service providers: – information can be found at the Centre for Change in Transition Services (Seattle University 2011). This 'model' is well-known and operated by the best services that achieve the best outcomes in terms of job placement, job retention, wages, hours and employer satisfaction. This model produces the greatest earned income and thus the maximum decrease in reliance on welfare.

One of the first Australian demonstrations of open employment from 1986 was the funding of Jobsupport in Sydney NSW. Jobsupport was funded to demonstrate that people with moderate intellectual disability could work in open employment given the right support and training. This demonstration continues today and is a 5-star service achieving placement and retention rates over 70%. They recently celebrated the fact that they are supporting over 500 people in jobs (Jobsupport 2011).

Real employment with a decent wage is an outcome for people with disabilities and the Productivity Commission should expect no less and support this. Article 27 of the UNCRPD clearly states that people with disabilities have the right to "gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible".

Transition programs

The Draft Report points to the NSW transition to work programs as an example of a program that works. NCID agrees with this and points again to the examples above of the need for successful transition to be an integrated part of the education system and for there to be expectations of employment outcomes for people with intellectual disability and their families from school.

Living independently – housing and support

There has been a lot of work done in gathering an evidence base on the types of housing and support which provides the best outcomes for satisfaction, inclusion, community connections and other factors important to the place where you live being a home (Institute for Family Advocacy and Leadership Development 2006). This evidence base is far too often ignored. The Draft Report does not deal with this issue. Funding current arrangements of specialist accommodation support will in many cases continue cluster housing and segregated accommodation. Article 19 of the UNCRPD clearly states people with disabilities will have choices equal to others, and not be in segregated settings.

The NDIS must start from a base which is inclusive and committed to the best outcomes for people with disabilities. NCID recommends that the Productivity Commission do further work in this area based on the evidence and develop clear principles of supported living for guiding the funding of support and housing. A key aspect of this must be the separation of funding for the rent or purchase of housing, from funding for support to live independently. The Draft Report acknowledges the conflict of interest in Disability Support Organisations acting as Service providers (Productivity Commission 2011, p7.15) yet does not recognise the inherent conflict of the landlord or housing provider being the same as the support provider. People with disabilities are captive recipients in this situation, unable to change one without losing the other.

Income Support

We agree with recommendation 4.6 that the NDIS should not fund income support. Howeve, we are concerned with the way the Commission is already limiting people with disabilities by this recommendation qualifying 'those with reasonable prospects of employment'. There is evidence that many people with disabilities, whom others would judge as having no prospects, can work given the right job and right supports.

Education

The Draft Report puts education as a mainstream service which is outside the NDIS but, like employment, is an area where some supports would be funded such as aids and equipment and personal care that would be used by the person with a disability no matter where they were (Productivity Commission 2011, p22). Also like employment, the terms of reference for the Productivity Commission (2011, p1.2) ask the commission to examine a support scheme that "provides for people to participate in education".

NCID is very concerned that the issues for people with disabilities and families when accessing education have not been addressed by the Productivity Commission. Education is a cornerstone to a good life, not only for people with disabilities, but for everyone. This is evidenced by the fact that primary and secondary education is compulsory in Australia. The UNCRPD Article 24 on Education clearly states the responsibilities that the Australian Government has in providing effective and inclusive education for people with disabilities. As stated in the section above on employment, the expectations, skills and transition models employed in schools are integral to people with disabilities then moving into open employment opportunities.

The NDIA and its case managers have a crucial role to play in assisting People with disabilities and their families to plan and manage their lives. Simply providing referral information to education supports is leaving what is often the most important external aspect of life journey up to the whim of the particular school a child attends. Currently a family in one area may have a school principal that says they have 0.4 FTE to support their child and work with the whole family to decide how best to use that support for maximum benefit of an inclusive education, while another family has a school that does not ask or include them in decisions about where supports should be used at all.

Article 24 section 2(e) of the UNCRPD states that governments must ensure "Effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion." NCID agrees that work on infrastructure, inclusive curriculum, policy, etc must be done within the mainstream education department – however ensuring effective individualised support is within the purview of the NDIS. It is particularly discriminatory when a person with physical disability can have the personal care supports needed to attend school provided through the NDIS, but a person with an intellectual disability who requires support with socialisation and understanding must rely on the lottery of the school. In reality, there are many people who require both personal care support and academic support at school and the teachers aide supplies both. For these people, it is certainly a waste of resources for that dual support to be split.

Whether the funding for the individualised support components of education come through the NDIS or the various education departments, a holistic case management approach as is envisioned with the NDIS must take into account and actively engage with schools to get the best outcomes for the people and families with whom they are working. The NDIA must also then take an active role in ensuring the relationships between schools and families are person-centred, effective and with goals of the child and parents valued. If the NDIA does not take on this role, there may well be ramifications for transition to work, independent living and community inclusion.

Chapter 5: Assessing care and support needs

The NCID interpretation of this chapter is that an assessment is done to determine eligibility for Tier 3 supports and then a person-centred plan is developed which includes a funding plan for the supports required. NCID is supportive of this model.

A concern is that this could be interpreted that the assessment and assessment tool is the person-centred plan. In this case, the detail in the Draft Report shows that there has not been a clear understanding of what person-centred planning covers and the process of person-centred planning.

Person-centred planning is intrinsically different to what is normally considered individual planning. Therefore, it requires a different approach. The NSW Department of Ageing Disability and Home Care commissioned a literature review in 2008 which highlights the leadership and cultural change required for true person-centred systems (Van Dam et al, 2008). 'Tick a box' assessments and medical reports are not person-centred planning even though they may be done with the person. The NDIS must have strategies which ensure training, leadership and support for people with disabilities, family members, service providers and bureaucrats to effect the cultural change needed to have true person-centred planning processes in place after initial assessment. The Community Living Initiative in WA is an excellent example of how this can work (Disability Services Commission WA 2010a).

Person-centred planning is where the person with a disability is driving the process and nominating the goals they aspire to as much as possible, with assistance to understand the system, find where supports are and detail the supports they need to reach their goals. It takes time and involves getting to know the person if you don't already. It is done with and by people who know the person with a disability. People with disabilities MUST be able to have family, friends and/or advocates they trust with them during the assessment and planning processes.

People with intellectual disability often have a range of communication issues which makes them particularly vulnerable. This group are more likely to answer an assessor with limited yes/no answers not having fully understood the process they are going through (Johnson et al, 2010, p79). Assessors and the assessment tools must be able to recognise and take this into account.

The Commission recommends a tool bag of assessments. A range of tools is used in person-centred planning because it is a fluid, flexible process where the engagement with the individual is at the forefront of how the planning is done. Person-centred planning can take 15 to 40 hours. This is quite different to assessment tools like 'I-can' or the In Control self-assessment or SIS which can be done in one day. Not every one will want a full person-centred plan but it must be seen as part of the process and funded accordingly. Saying you have a person-centred approach and person-centred planning, but only funding 2 to 3 hours of time for that to occur in, shows a gross misunderstanding of person-centred planning.

Further research is currently being done on a self-assessment tool by Danielle Cheesman and Ros Madden at the University of Sydney (PWDA e-bulletin April 2011) based on the ICF framework. This new research should be considered when looking at assessment rather than dismissing self-assessment entirely.

When working on the assessment part of this process, there must be learnings from the problems that have been encountered with the Job Capacity Assessment (JCA) process and current assessment processes in use in other areas. The JCA process has not worked for people with intellectual disability and there is concern that this may have similar problems when being delivered through a centralised agency. In particular, one of the biggest problems has been the mismatch of the skills and expertise of the assessor with the issues and barriers of the person with the disability (Nevile 2010).

Everyone being treated the same will not work because of the diversity of disability, and too many different assessment tools and discretion by the assessor will not work because of the variation which will occur. A combined self-assessment and independent assessment as detailed by the In Control Model addresses both these issues.

NCID recommends that the Commission adds to its recommendations that multiple trials of assessment tools be done and to have an expert group (including people with disabilities and families) to sort through the best assessment process and how and where person-centred planning fits into this process.

Chapter 6: Who has the decision-making power?

The Draft Report has three key ways to put people with disabilities in control:

- Individual Budget Allocation with choice of provider and/or intermediary
- Person-centred planning
- Self-directed funding

The Draft Report does not identify person-centred planning specifically as a way of shifting power; yet it is part of the culture shift to seeing the skills, abilities and expertise of the person with a disability. The way funding is managed is an important tool in the shift of power and control.

In separating out the self-directed funding as an option for those assessed as having the capacity, the Draft Report has deviated from the intent of the UNCRPD, and the intent of keeping people with disabilities front and centre.

Self-directed funding should be the default option, with people knowing the dollar amount of their package and what that translates to in services and supports. Then they direct how they want to manage it, whether they want to cash out all or some. Support for managing funding and support for decision-making are essential for all people with disabilities to be able to take the option of cashing out if they wish. (In Control Australia 2011)

People with disabilities and families who don't want to 'cash out' initially should be able to access training and information to build capacity for them to choose that in the future. It must not be automatically presumed that people with intellectual disability will not have the capacity to do this or that they will not be able to learn to do so.

The flexibility of moving from 'cashed out' or not at different times must be available. Discretionary decision-making at local level for people’s changing needs must be available for all people receiving support packages, not just those receiving funds directly.

People with disabilities and families who have chosen different options should be part of ongoing evaluation groups in many different localities and be listened to and help shape and monitor the choice, control and decision-making they really have. There are already some families and people with disabilities who have expertise in this area — this can be shared and built upon. At the BiG Event 2011, convened by In Control Australia, participants were keen to have more information on building their capacity to self-direct. Popular sessions at the event were those run by people that shared their stories and experiences of self-direction. People expressed that they would like the chance to have both formal and informal networks to explore these learnings.

There needs to be more made of the use of support organisations, brokers and other methods of being in control. Currently, the Draft Report talks about 'cashing out' or the use of a third party to broker funding. The In Control model has up to six combinations or options for how a person with a disability can be in control and supported to be in control of their support package (In Control Australia 2011). There must be the ability for new ways of self-direction to emerge.

Chapter 7: Governance of the NDIS

People with disabilities must be an integral part of governance and on the Board as per Article 4 of the UNCRPD. There is an underlying assumption made in the report that people with disabilities would not have the expertise or skills to be on the Board. This is not the case.

The Advisory group must feed in to the Board and have representation from people with intellectual disability who are supported appropriately to participate. There must also be people from regional and remote areas from different States. People with disabilities are the beneficiary of the NDIS; therefore, they should hold the majority of any advisory board.

There is research and evidence which shows that, with the right support, people with intellectual disability can participate and contribute to high level advisory councils and boards (Regan 2010; Frawley and Bigby 2010).

Chapter 10: Collecting and using data under the NDIS

Good data and research are necessary for evidence-based approaches. The Productivity Commission and Draft Report state this emphatically. Yet, in the area of employment and accommodation, the recommendations do not show that they have taken into account the evidence which shows the best outcomes for people with disabilities.

Research and data must never be used to undermine an individual or punish an individual. Again, there is a concern that a centralised agency will use data for fraud detection to the detriment of all people using the system. If anomalies are found, there needs to be an engagement with the person and their networks to ensure there is an understanding of a situation.

People with disabilities and carers should 'own' data about themselves and be able to take it with them and give permission for others to use it. There needs to be extra safeguards for people with intellectual disability about who can use and see data about them and ensuring there is understanding of what that means.

Chapter 11: Early intervention

NCID supports the emphasis in this chapter on the need for developmental support/ early intervention that is evidence-based. Early Intervention is often seen as only relating to the early years of childhood. Interventions may be needed at all times, particularly at life transition stages. To recognise the intervention needs of all people with disabilities the term ‘developmental support’ should be used.

For people with intellectual disability and their families, an essential part of developmental support is support to the family that is positive and about building a supportive family environment for the child. For example, the time of diagnosis is often filled with information for a family that is medically-based and focused on the deficiencies. Yet this is a time when the family needs to get information about the potential of their child, and the ability of their child to lead a successful and fulfilling life. The Draft Report did give one example of a service that provided this type of support - the 'Welcome program' through Novita's Children Services (Productivity Commission 2011, p11.7). Many other groups such as the Down Syndrome Association of Victoria (2011) also provide this peer support and empowerment, but other children with intellectual disability do not get the support. NCID believes this type of support to families as part of the developmental support/early intervention is extremely important in families having expectations for their child to have a good life and should be provided, encouraged and developed through the Disability Support Organisations ensuring no group is left out.

Therapy is another essential element of developmental support/ early intervention. One of the issues currently in many regional areas and in fact nationally is the shortage of Allied Health professionals, particularly Physiotherapists, Occupational Therapists, and Speech Therapists (Australian Health Workforce Advisory Committee 2004, p70). We know from families experience that support is funded as therapists' hours rather than therapy. With the shortage of therapists, this has meant that government and service providers are often holding funds until a therapist can become available. This can be for up to two years while families are waiting for therapy services. In these instances, the emphasis must be on the provision of therapy. This change in emphasis allows for creative solutions such as bringing in therapists from other areas to train families, gym trainers, therapy assistants, and support workers in the required therapy; or families being funded to go to metropolitan areas for intensive therapy sessions.

Developmental support/early intervention for people with intellectual disability must be timely, appropriate and family-focused to make a difference.

Chapter 12: Where should the money come from? Financing the NDIS

NCID supports funding for the NDIS coming from general revenue via a legislated formula, which takes into account future needs, is based on good data and on real costs.

Chapter 16: NIIS

There is a concern that having a separate system where there may continue to be different funding levels is inequitable. This insurance system is inherently medical-based with medical-based assessments. The NIIS should be phased into the NDIS as soon as possible.

Chapter 17: Implementation

Supplemental funding for those worst off, while the NDIS is introduced as detailed in Recommendation 17.3, is needed. There needs to be close monitoring of funding levels to ensure there will be enough funding to adequately meet needs or we will retain a crisis driven competitive system for funding. No person with a disability should be worse off under the new system and we support this recommendation. However, we are also concerned that this supplementary funding does not become an excuse to delay implementation of the NDIS.

The Draft Report recommends a trial in one locality to test tools and systems. However, each State is starting at a different point with different levels of useful infrastructure in place. It would therefore be much more useful to have a small trial in every State and see how much change would be required in the different jurisdictions when rolling out nationally.

Recommendation 17.4 puts a date of 2020 for an evaluation by an independent public inquiry. An Action Learning approach and environment should be considered through use of an on-going evaluation framework to enable learnings and change required along the way. We don't want to wait 5 years or more to review and change aspects which are not working. An independent public inquiry would be best placed 3-5 years after implementation.

References

Australian Health Workforce Advisory Committee 2004, The Australian Allied Health Workforce – An Overview of Workforce Planning Issues, AHWAC Report 2006.1, Sydney

Bigby, C., Fyffe, C and Mansell, J. 2006, From ideology to reality: Current issues in implementation of intellectual disability policy. Proceedings of the Roundtable On Intellectual Disability Policy. Bundoora: LaTrobe University.

Department of Human Services 2011, Multiple and Complex Needs Initiative, State Government of Victoria Department of Human Services viewed in 2011 at http://www.dhs.vic.gov.au/operations/multiple-and-complex-needs-unit

Disability Services Commission WA 2010, Reporting on disability: words that work - a guide for media Disability Services Commission WA
available at http://www.disability.wa.gov.au/mediaadvertising.html

Disability Services Commission WA 2010a, Community Living Initiative, Disability Services Commission WA viewed in 2011 at http://www.disability.wa.gov.au/forindividuals/clivinginitiative.html

Down Syndrome Association of Victoria 2011, Support for families, Down Syndrome Association of Victoria, viewed in 2011 at http://www.dsav.asn.au/Families/support.html

Frawley, P., and Bigby, C. 2010, Making it Real: Participation of People with Intellectual Disability on Government Advisory Boards. In Bigby, C., and Fyffe, C (2010). More than Community Presence: Social Inclusion for People with Intellectual Disability. Proceedings of the Fourth Annual Roundtable on Intellectual Disability Policy. Bundoora: La Trobe University.

Hume, J. 1994, Media Guidelines Disability Council of NSW, Sydney
available at http://www.disabilitycouncil.nsw.gov.au/archive/94/hume.pdf

In Control Australia 2011, In Control Australia website, hosted by the Julia Farr Association, viewed in 2011 at http://www.in-control.org.au/default.asp

Institute of Family Advocacy and Leadership Development 2006, Presenting the Evidence: Accommodation and support for People with disabilities, in Interaction, Volume 19 Issue 3, 2006, Australian Institute on Intellectual Disability

Jobsupport 2011, Jobsupport Homepage, Jobsupport viewed in 2011 at http://www.jobsupport.org.au/main/component/option,com_frontpage/Itemid,1/

Johnson, H., Douglas, J., Bigby, C. and Iacono, T. 2010, The Pearl in the Middle. A Case Study of Social Relationships with an Individual with a Severe Intellectual Disability. In Bigby, C., and Fyffe, C (2010). More than Community Presence: Social Inclusion for People with Intellectual Disability. Proceedings of the Fourth Annual Roundtable on Intellectual Disability Policy. Bundoora: La Trobe University.

Law Reform Commission of Western Australia 2009, Court Intervention Programs, Final Report, Project No. 96 Government of Western Ausralia
Available at http://www.lrc.justice.wa.gov.au/2publications/reports/P96-FR.pdf

Mental Health Commission WA 2011, People with Extremely Complex Needs Project, State Government of Western Australia Mental Health Commission viewed in 2011 at http://www.mentalhealth.wa.gov.au/Initiatives_and_Projects/pecn.aspx

National People with disabilities and Carer Council 2009, Shut Out: The Experience of People with disabilities and Their Families, Commonwealth of Australia

Neill, M. 2007, Guidance and Resources on Alzheimer's Dementia for Carers of People with Down's Syndrome viewed in 2011 at http://www.intellectualdisability.info/mental-health/alzheimers-dementia-what-you-need-to-know-what-you-need-to-do

Nevile, Dr A. 2011, Response to Employment Services 2012 Consultation, Social Policy Action Research Centre, Crawford School of Economics and Government, The Australian National University, Canberra
Available at http://www.crawford.anu.edu.au/sparc/pdf/2011/Response_to_Employment_Services_2012_sparc.pdf

NSW CID 2010 Proposal for specialised services to enhance the capacity of the mainstream health system to provide equitable and cost effective health care to people with intellectual disability, viewed in 2011 at http://www.nswcid.org.au/images/pdfs/hth%20prop%20web.pdf

NSW CID 2011a, New South Wales Council on Intellectual Disability Speak Out Reach Out Committee Submission to the Productivity Commission's Inquiry into Disability Care and Support , viewed in 2011 at http://www.nswcid.org.au/images/pdfs/SORO_PC_SUB.pdf

NSW CID 2011b, Supporting people with intellectual disability with alcohol and/or drug issues viewed in 2011 at http://www.nswcid.org.au/standard-english/se-pages/health.html

Prasher, V.P. and Routhu, S.K. 2003, Epidemiology of Learning [Intellectual] Disability and Comorbid Conditions in Psychiatry, Volume 2:8, August 2003 The Medicine Publishing Company.

Productivity Commission 2011, Disability Care and Support, Draft Inquiry Report, Canberra.

PWDWA 2009, Annual Report 2008-2009, People with disabilities (WA) Inc.

PWD 2010, People with disabilities Australia Annual Report 2009 – 2010, People with disabilities Australia Inc.

PWD 2011, The Productivity Commission Inquiry into Disability Care and Support, PWD e-bulletin 11 April 2011

Regan, C. 2010, Practicing what we preach, Interaction Volume 23 Issue 3, Australian Institute on Intellectual and Developmental Disabilities.

Richardson, N. 2009, Writing about disability: Victoria's Bar None campaign,Asia Pacific Media Educator, 19, 2009, 37-42.
Available at:http://ro.uow.edu.au/apme/vol1/iss19/5

Seattle University 2011, Centre for Change in Transition Services , Seattle University and Office of the Superintendent of Public Instruction available at http://www.seattleu.edu/ccts/default.aspx?id=34548

UNCRPD, United Nations Convention on the Rights of People with disabilities

Van Dam, T., Ellis, J., Sherwin, J. 2008, Person-Centred Planning: A Review of the Literature, NSW Department of Ageing, Disability and Home Care, NSW

Winther, T. 2011, Peddling Pity, ABC Ramp Up Opinion, Australian Broadcasting Corporation, viewed in 2011 at http://www.abc.net.au/rampup/articles/2011/03/22/3170458.htm

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Tuesday, 3 May 2011

"To promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent human dignity."

UN Convention on the Rights of Persons with Disabilities

Statement by NCID in relation to the inclusion of people with intellectual disability as a recognised group within the NDIS criteria.

The Draft Productivity Commission Report into Long Term Support for People with Disability states:

> *Individuals receiving individually tailored, funded supports should be Australian residents, have a permanent disability, (or if not a permanent disability, be expected to require very costly disability supports) and would meet one of the following conditions:*
>
> - *have significant difficulties with mobility, self-care and/or communication*
> - ***have an intellectual disability***
> - *be in an early intervention group, comprising:*
>   - *those for whom there was a reasonable potential for cost-effective early therapeutic interventions (as in autism and acquired brain injury)*
>   - *those with newly diagnosed degenerative diseases for whom early preparation would enhance their lives (as in multiple sclerosis)*
> - *have large identifiable benefits from support that would otherwise not be realised, and that are not covered by the groups above. Guidelines should be developed to inform the scope of this criterion.*

NCID is strongly supportive of Intellectual Disability being maintained as a determining criterion and calls upon all people with disability, family members and organisations to support this position.

For over 10 years NCID, our Agency Members and the intellectual disability community have demonstrated through a strong evidence base that ALL people with intellectual disability have complex and significant support needs.[1] [2]

The American Association on Intellectual and Developmental Disabilities (AAIDD), and international authority on this subject states:

> "Providing supports to people with intellectual disability enables their functioning in typical life activities in mainstream settings but does not eliminate the possibility that they will continue to need ongoing supports. Put another way, if supports were removed, people with intellectual disability would not be able to function as successfully in typical activities and settings."

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[1] See, *Intellectual Disability: Definition, Classification, and Systems of Supports* (Eleventh edition), AAIDD.

[2] The significant support needs of people with intellectual disability is recognised internationally with distinct policy initiatives, eg, Valuing People in the UK and the President's Council on Developmental Disabilities in USA.

We believe the failure to recognise this evidence will inevitably lead to significant disadvantage for people with intellectual disability.[3]

We are gravely concerned by recent uninformed comments that have sought to minimise the disadvantage experienced by people with intellectual disability by;

- reducing the complex needs of people with intellectual disability to '*social and living skills*'
- stating that people with intellectual disability have '*lesser or no support needs*'
- stating that people with intellectual disability should be '*removed from the above categories*' in Productivity Commission Report.

Such comments (without any evidence being put forward to substantiate them) demonstrate a complete lack of understanding of intellectual disability and the support needs of people with intellectual disability. For example, intellectual disability is the only disability group that has objective criteria that is not graduated through a spectrum; the definition has a clear boundary and everyone within that definition requires support.

"To promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent human dignity."

UN Convention on the Rights of Persons with Disabilities

> An assessment for "intellectual disability" requires an individual to meet two rigorous assessments.
> An assessment of intellectual function that is 2 standard deviations below the mean intelligence for the population. That is an IQ of less than 70.
> An assessment of adaptive behaviour that is 2 standard deviations below the mean of adaptive behaviour for the population. Adaptive behaviour is the collection of conceptual, social, and practice skills that have been learned and are performed by people in their everyday lives.
>
> People with intellectual disability and their families have already undergone substantial assessment that clearly indicates the need for ongoing support to participate in typical activities and settings.

NCID calls upon all people with disability, family members and organisations to reject any attempt to remove intellectual disability from the Productivity Commission's proposed eligibility framework, and to support the position of the recognised peak body in this area.

NCID, our Agency Members and the intellectual disability community have won significant advancements for people with intellectual disability over the years, that is, additional medicare items, additional employment support, etc, and we will continue to advocate strongly for evidence based responses to the support needs for all people with intellectual disability; and all people with disability.

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[3] See, *People with Intellectual Disability in a Whole of Disability Service Framework,* Interaction Vol 23 Issue 3; and *Employment of People with Intellectual Disability,* Interaction Vol 22 Issue 3