



Council for  
Intellectual Disability

# Submission on Productivity Commission Issues Paper – NDIS Costs

**April 2017**

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## WHO WE ARE

For 60 years, NSWCID 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 must have a majority of people with intellectual disability and we actively involve people with an intellectual disability in all aspects of our work.

Especially in the last 10 years, we have had a heavy focus on the development of the capacity of people with intellectual disability to not only make their own decisions but also lead our organisation. The NSW government has funded our *My Choice Matters* project which is focused on developing the ability of people with intellectual disability to control their own lives in accordance with the principles of choice and control that are inherent in the National Disability Insurance Scheme.

We have two representatives on the Intellectual Disability Reference Group of the National Disability Insurance Agency.

[www.nswcid.org.au](http://www.nswcid.org.au)

[www.mychoicematters.org.au/](http://www.mychoicematters.org.au/)

## PRELIMINARY COMMENT

From the start, we have been strong supporters of the development of the NDIS and we continue to see scheme as having a fundamental capacity to improve the lives of people with disability around Australia. In the submission, we seek to be constructive critics so as to assist the development of the scheme to its full potential.

Due to time pressures, this submission focuses on issues where we are best able to comment. Questions that we have not answered are in square brackets [ ].

## SCHEME COSTS

***Are there any cost drivers not identified that should be considered in this study?  
If so:***

- how do they impact costs in the short and long term?***
- how, and to what extent, can government influence them?***

Two cost drivers are missing. First, there is the extent to which LACs and other ILC services are able to reduce reliance on NDIS funding packages by supporting people to meet their needs through mainstream services and other general community supports. In the absence of robust availability of ILC services, more people will need

NDIS packages and the size of those packages is likely to be higher due to unmet comparatively minor needs escalating for want of those needs being met.

Second, there is the extent to which people who need NDIS packages receive any necessary support to navigate their way into the scheme. The majority of potential participants, with support from family where needed, may be well aware of the NDIS and seek it out of their own initiative. However, many people are not in this category, notably including people with intellectual disability who live isolated lives on society's fringe and whose initial tendency will be to resist the idea of another government agency interfering in their lives. Such individuals generally need substantial support from a trusted worker or advocate to introduce them to the NDIS and support them through NDIS processes. See:

- Our position statement  
[http://www.nswcid.org.au/images/pdf/Fringe\\_posn\\_statement\\_150315.pdf](http://www.nswcid.org.au/images/pdf/Fringe_posn_statement_150315.pdf)
- Our publication Participants or Just Policed pages 74-76 at  
[http://www.nswcid.org.au/images/pdf/Participants\\_or\\_just\\_policed\\_614.pdf](http://www.nswcid.org.au/images/pdf/Participants_or_just_policed_614.pdf)

If people do not receive this support early, their support needs may well escalate so that they need larger packages later on. Also, there is a cost/benefit to governments in meeting the disability support needs of such people and saving money in the justice, health and other service systems. See the UNSW/PWC study at

<http://www.daru.org.au/wp/wp-content/uploads/2013/08/Justice-Reinvestment-Report-Cost-benefit-analysis-13-08.pdf>

***Why are utilisation rates for plans so low? Are the supports not available for participants to purchase (or are there local or systemic gaps in markets)? Do participants not require all the support in their plans? Are they having difficulty implementing their plans? Are there other reasons for the low utilisation rates?***

For people with intellectual disability and, in many cases their families, they need assistance to engage with support services they need. Skilled and adequate assistance from local area coordinators and support coordinators is often not available at this stage of the NDIS's development.

***Why are more participants entering the scheme from the trial sites than expected? Why are lower than expected participants exiting the scheme?***

Contrary to this question, in the Hunter trial site, there was a major shortfall in participants entering the scheme. From our experience with that trial site, we would see this shortfall as having flowed from a lack of adequate outreach and engagement with potential participants, in particular people with intellectual disability who live isolated lives on society's fringe. This includes people whose self management impairments lead to contact with the criminal justice system, very few of whom became participants in the Hunter trial. By comparison, we understand that in Barwon, there was a much more robust and collaborative arrangement with justice services leading to far more people with criminal justice involvement accessing the scheme.

Increased exit from the scheme can be enhanced by:

- greater capacity building for individuals, in particular for people with intellectual disability for whom capacity development inevitably takes time;
- increased economic participation, which relies on an employment sector which is better skilled than at present in supporting people with disability.

*[What factors are contributing to increasing package costs?]*

### ***Why is there a mismatch between benchmark package costs and actual package costs?***

The reference packages for people with intellectual and other similar disabilities do not have a robust research backing. We assisted the NDIA to develop the methodology for these packages and emphasised at the time that they should not be used as any more than a starting point for considering individual needs.

At present, there is also inconsistency in application of benchmarking. This is partly due to a lack of adequate and appropriate training for planners and inadequate benchmarking for people who have complex needs

## **SCHEME BOUNDARIES**

### **Eligibility for the NDIS**

*[To what extent have the differences in the eligibility criteria in the NDIS and what was proposed by the Productivity Commission affected participant numbers and/or costs in the NDIS?]*

*[Are there other aspects of the eligibility criteria of the NDIS that are affecting participation in the scheme (to a greater or lesser extent than what was expected)? If so, what changes could be made to improve the eligibility criteria?]*

### ***To what extent is the speed of the NDIS rollout affecting eligibility assessment processes?***

In NSW, the current process of transition of 72,000 existing disability service clients into the NDIS is greatly impinging on the capacity of the NDIA to engage in a reasonable quality of eligibility assessment and planning.

*[Is the ECEI approach an effective way to ensure that those children with the highest need enter into the NDIS, while still providing appropriate information and referral services to families with children who have lesser needs?]*

*[What impact will the ECEI approach have on the number of children entering the scheme and the long-term costs of the NDIS?]*

*[Are there other early intervention programs that could reduce long-term scheme costs while still meeting the needs of participants?]*

## The intersection with mainstream services

*Is the current split between the services agreed to be provided by the NDIS and those provided by mainstream services efficient and sufficiently clear? If not, how can arrangements be improved?*

The split in responsibilities between the NDIS and justice services is both unclear and inefficient. See below.

*Is there any evidence of cost-shifting, duplication of services or service gaps between the NDIS and mainstream services or scope creep in relation to services provided within the NDIS? If so, how should these be resolved?*

*How has the interface between the NDIS and mainstream services been working? Can the way the NDIS interacts with mainstream services be improved?*

There is a wide range of problems here.

Mainstream services remain often inaccessible and inappropriate for people with intellectual disability.

**The National Disability Strategy 2010-2020 (NDS) has a very low profile in mainstream government agencies and action on it has been very inadequate.**

Our systemic work includes a priority on improving health care for people with intellectual disability.

There is wide-ranging research in relation to physical and mental health disparities faced by people with intellectual disability including recent research showing 38% of deaths of people with intellectual disability in NSW being potentially preventable and high rates and high costs of emergency and hospital presentations. People with intellectual disability have very high rates of mental illness but very poor access to appropriate mental health services. See attached research summary

If people with intellectual disability are physically or mentally unwell, their disability support needs will tend to be higher.

The National Disability Strategy specifically calls for “universal health reforms and initiatives [to] address the needs of people with disability”. “System changes flowing from health reforms and initiatives across Australia provide important opportunities to improve responses to the health needs of people with disability....Key health reforms with implications for people with disability include.... mental health.”

In fact, health reforms commonly do not address the needs of people with intellectual disability. For example,

- The rollout of the Australian Government’s mental health reforms that were announced in late 2015 lacked a focus on people with intellectual disability. Our initial attempts to address this with the Department of Health were fruitless. Eventually, after strong advocacy to Minister Ley, some useful first steps have occurred including mentions of people with intellectual disability in some guidelines for Primary Health Networks.

- The 2016 consultation draft for the 5th National Mental Health Plan which was prepared by an interjurisdictional committee did not even mention people with intellectual disability in a list of equity groups let alone include any substantial focus on their mental health needs. We are pleased to say that the NSW Government has now advocated for people with intellectual disability to be a priority group in the final plan.

**All too often, both the NDIS and mainstream services seem focused on demarcation rather than collaboration.** In fact, it is to the advantage of service systems to work together. For example, if a person's health care needs are met, their disability support needs will often be less. And good disability support will lead to healthier lives. Win for the health system! Win for the NDIS! Win for the individual!

**The NDIS Interface Principles with Justice assume that justice or "other" services provide a wide range of supports that they do not commonly provide** and could not provide in any systematic way without major budget enhancements.

These include:

1. Cognitive and psychiatric assessments for court sentencing or diversion.
2. Accessible legal assistance
3. "Offence specific interventions.... which are not clearly a direct consequence of the person's disability".
4. "Intensive case coordination ... where a significant component of the case coordination is related to the justice system".
5. Early identification and primary intervention programs.

**In NSW, major problems are flowing from the bilateral agreement with the Commonwealth whereby NSW is handing over its whole disability budget for participant plans whereas a range of essential services that were funded out of that disability budget will not be funded by the NDIS.** These include:

1. A range of health services including for example:
  - a. a statewide network of specialist nurses who support good health care in disability services and enhance linkage with health services;
  - b. regional psychiatry clinics which are an essential complement to behaviour support for many people with intellectual disability;
  - c. access to the research validated CHAP assessment tool for annual health assessments of people with intellectual disability;
  - d. a clinic in Newcastle which brings together a range of medical specialists to address complex health needs of people with intellectual disability.
  - e. The NSW Ombudsman has emphasised the need for these services to continue in its most recent report on deaths in care of people with disability. <http://www.ombo.nsw.gov.au/news-and-publications/publications/annual-reports/reviewable-deaths-vol-1/report-of-reviewable-deaths-in-2012-and-2013-volume-2-deaths-of-people-with-disabilities-in-care>

2. Individual and systemic advocacy services.
3. The Criminal Justice Support Network of the Intellectual Disability Rights Service. This service provides support to people with intellectual disability in police interviews and in court including often facilitating links to support services and the NDIS.
4. Assessments of disability to underpin NDIS eligibility. These are stated to be the responsibility of health services whereas to date assessments of eligibility for disability services in NSW have generally been carried out by psychologists employed in those services.
5. Also, experience to date strongly suggests that the NDIA will not adequately fund the needs of clients of the Community Justice Program which is a disability services program focused on meeting the disability needs of people with intellectual disability and very serious histories of offending. The NDIA perceives that justice services should be meeting a major part of the needs of this group but there is no NSW funding source for this.

**The NSW Trustee and Guardian, which acts as a Tribunal appointed financial manager for thousands of people with disability, has recently had a “transformation” which has involved a 20% budget cut.** This has led to a narrowing of service scope including abolition of many disability adviser positions. The disability advisers were a resource for financial managers in relation to spending that might enhance quality of life and provided significant crisis intervention for clients of the Trustee in a wide range of situations.

*[How will the full rollout of the NDIS affect how mental health services are provided, both for those who qualify for support under the scheme and those who do not?]*

***What, if anything, needs to be done to ensure the intersection between the NDIS and mental health services outside the scheme remains effective?***

For people who have both intellectual disability and a mental health problem, the intersection between the roles of disability and mental health services has never been satisfactory. Mental health services tend to refuse access to people with intellectual disability and lack necessary skills. See the background paper and communiqué from the National Roundtable on the Mental Health of People with Intellectual Disability at <http://www.nswcid.org.au/what-we-do/mental-health.html>

***Is the range and type of services proposed to be funded under the ILC program consistent with the goals of the program and the NDIS more generally?***

There is a major gap here. Many people would not need to become NDIS participants if the ILC role included ad hoc problem-solving and crisis disability support which would have a strong effect on reducing escalation of disability support needs. Many people with intellectual disability do not need disability support on a day by day basis but do need access to support when faced with a particular life problem, crisis or transition.

***What, if anything, can be done to ensure the ILC and LAC initiatives remain useful and effective bridging tools between services for people with disability?***

For people with intellectual disability, bridging needs to be a very active process rather than just referral and arranging an appointment. The self-management impairments commonly experienced by people with intellectual disability will prevent them from being able to follow through on referrals. For people who live isolated lives, these issues are particularly important as they will often tend to be suspicious of new support providers.

Also, valued and trusted providers of ILC initiatives are very important for people with intellectual disability and this will be impacted on by ILC providers' lack of certainty of funding. Greater commitment to medium-term and long-term funding for ILC providers would result in better outcomes for people and for the Scheme, including in diverting people from becoming funded participants.

***Is the way the NDIS refers people who do not qualify for support under the scheme back to mainstream services effective? If not, how can this be improved?***

Often not for people with intellectual disability. See answer to previous question.

## **The intersection with the National Injury Insurance Scheme**

*[How will the NIIS affect the supply and demand for disability care services?]*

*[What impact will the full establishment of the NIIS have on the costs of the NDIS?]*

*[Are sufficiently robust safeguards in place to prevent cost shifting between the NIIS and the NDIS?]*

## **PLANNING PROCESSES**

***Is the planning process valid, cost effective, reliable, clear and accessible? If not, how could it be improved?***

In the current very fast transition into the NDIS in NSW, the planning process has been very rushed and therefore often leading to invalid results. To conduct valid planning with a person with intellectual disability requires preplanning and support for the person, the planner reading background assessments and existing plans, face-to-face planning, if necessary over a number of sessions, and planners with skills in communicating and understanding the needs of people with intellectual disability. All of these elements are often lacking.

In current practice, planning is often centred on a family member of a person with intellectual disability due to the process being rushed and/or because of perceptions about the capacity of the person to engage in the process. Substitute decision-making should not be occurring in planning without the safeguards in the nominee provisions of the NDIS legislation. However, those safeguards are rarely invoked and de facto substitute decision-making is common.

*[How should the performance of planners be monitored and evaluated?]*



## Assessment tools

***Do NDIA assessment tools meet these criteria? What measures or evidence are available for evaluating the performance of assessment tools used by the NDIA?***

NDIA assessments are rudimentary compared with good practice needs assessments of people with intellectual disability. For good practice, see the research validated I-CAN Of the Centre for Disability Studies. <https://www.i-can.org.au/info.php>

For some people with complex needs, a range of assessments is needed from a multidisciplinary perspective.

*[What are the likely challenges for monitoring and refining the assessment process and tools over time? What implications do these have for scheme costs?]*

## Creating a support package

***Are the criteria for participant supports clear and effective? Is there sufficient guidance for assessors about how these criteria should be applied? Are there any improvements that can be made, including where modifications to plans are required?***

The widely variable components of support packages for people with quite comparable needs strongly suggests that current criteria and processes are not adequately clear and effective.

***To what extent does the NDIA's budget-based approach to planning create clear and effective criteria for determining participant supports? To what extent does it lead to equitable outcomes for participants? What improvements could be made?***

We provided the NDIA with some assistance in its development of reference packages for people with intellectual disability. The reference packages are not based on any substantial research methodology. They should not be used as any more than a starting point for development of an individual support package.

Budget-based planning is at odds with person/family-centred planning, which has been proven to be the most effective way to achieve better outcomes for people with disability. An inflexible "shopping list" approach to planning leads people to be less creative about combining natural and paid supports.

*[What implications do the criteria and processes for determining supports have for the sustainability of scheme costs?]*

***Are the avenues for resolving disagreements about participant supports appropriate? How could they be improved?***

The avenues are appropriate but we have received much negative feedback in relation to how they are currently working in practice, for example:

- Internal reviews taking up to 10 weeks and without any contact with the person/family by the reviewer.
- Inadequate internal reviews including people simply receiving a new plan in the mail without explanation. In some cases, these plans did not include any substantial change.

## **MARKET READINESS**

### **Will the workforce be ready?**

***What factors affect the supply and demand for disability care and support workers, including allied health professionals? How do these factors vary by type of disability, jurisdiction, and occupation? How will competition from other sectors affect demand (and wages) for carers? What evidence is there from the NDIS trial sites about these issues?***

There is a fast looming crisis in relation to supply of a skilled workforce for people with intellectual disability and complex behavioural needs. There has never been adequate workforce for this group, either disability support or behaviour practitioners and therapists. The problem is currently being exacerbated in NSW due to the tendering out of the State disability services program which has to date been the main source of expertise and last resort provider for people with complex needs. Non-government services generally do not have a strong history in this field and whether they will be able to meet all complex behavioural needs is questionable. Also, private behaviour support firms report great difficulty recruiting skilled practitioners as those practitioners prefer to work for government and are therefore seeking jobs in non-disability government agencies.

*[How will an ageing population affect the supply and demand for disability carers (including informal carers)?]*

*[Is increasing the NDIS workforce by 60 000-70 000 full time equivalent positions by 2019-20 feasible under present policy settings? If not, what policy settings would be necessary to achieve this goal, and what ramifications would that have for scheme costs?]*

***How might assistance for informal carers affect the need for formal carers supplied by the NDIS and affect scheme costs?***

Strong support for informal carers may reduce the demand for formal paid carers. However, informal carers are entitled to have usual scope for employment and recreation rather than being used as a free substitute for the NDIS.

*[To what extent is the supply of disability care and support services lessened by the perception that caring jobs are poorly valued? If such a perception does exist, how might it best be overcome?]*

*[What scope is there to expand the disability care and support workforce by transitioning part-time or casual workers to full-time positions? What scope is there to improve the flexibility of working hours and payments to better provide services when participants may desire them?]*

*[What role might technological improvements play in making care provision by the workforce more efficient?]*

*[What are the advantages and disadvantages of making greater use of skilled migration to meet workforce targets? Are there particular roles where skilled migration would be more effective than others to meet such targets?]*

## **Will providers be ready?**

*[Are prices set by the NDIA at an efficient level? How ready is the disability sector for market prices?]*

*[How do 'in-kind' services affect the transition to the full scheme and ultimately scheme costs?]*

*[What is the capacity of providers to move to the full scheme? Does provider readiness and the quality of services vary across disabilities, jurisdictions, areas, participant age and types/range of supports?]*

### ***How ready are providers for the shift from block-funding to fee-for-service?***

There is a major problem here in relation to services for people with disability who have contact with the criminal justice system. Continuity of support and relationships between worker and person are vital to effective support. However, the current NDIA practice of suspending funding when a person is incarcerated counts against providers being able to meet such needs. The result is likely to be lack of continuity of support, escalation of disability related problems with the law and escalation of disability support needs.

*[What are the barriers to entry for new providers, how significant are they, and what can be done about them?]*

***What are the best mechanisms for supplying thin markets, particularly rural/remote areas and scheme participants with costly, complex, specialised or high intensity needs? Will providers also be able to deliver supports that meet the culturally and linguistically diverse needs of scheme participants, and Aboriginal and Torres Strait Islander Australians?***

We are highly sceptical about whether the market will provide adequate skilled providers to work with people with complex behavioural needs including people who have contact with the criminal justice system. The NDIA needs a very robust system to avoid market failure which may include commissioning of services and, in some cases, block funding.

*[How will the changed market design affect the degree of collaboration or co-operation between providers? How will the full scheme rollout affect their fundraising and volunteering activities? How might this affect the costs of the scheme?]*

## **Will participants be ready?**

***How well-equipped are NDIS-eligible individuals (and their families and carers) to understand and interact with the scheme, negotiate plans, and find and negotiate supports with providers?***

People with intellectual disability and their families are very often ill equipped to do these things. A cognitive impairment inherently makes it difficult for a person to deal with NDIS processes and many families also find them challenging and confusing. Many people do not have involved families.

There have been some very positive initiatives to support individuals and families to prepare for the NDIS including the funding of disability support organisations and the New South Wales Government's funding of our My Choice Matters project. However, the reach of these initiatives to date is limited compared with the need and the current ILC budget will be inadequate to meet even existing investment in this area.

## **GOVERNANCE AND ADMINISTRATION**

*[Do existing administrative and governance arrangements affect (or have the potential to affect) the provision of services or scheme costs? What changes, if any, would improve the arrangements?]*

*[To what extent do the reporting arrangements help to achieve the financial sustainability of the scheme? Are they too onerous or do they need to be expanded?]*

*[Does the way that the NDIA measures its performance affect the delivery of the NDIS?]*

*[To what extent do the existing regulations provide the appropriate safeguards and quality controls? Can these arrangements be improved?]*

*[Are there appropriate and effective mechanisms for dealing with disputes with the NDIA?]*

***Is the NDIA's target for operating costs (as a percentage of total costs) achievable? Is it practical? Should it vary over the life of the scheme?***

The NDIA's target for operating costs has been a major impediment to the quality of scheme development and individual planning to date. The target has had very negative implications in areas including timely recruitment of LACs and planners and the agency having adequate staff to proactively develop systemic strategies and practices, for example in relation to people with complex needs.

***How appropriate, effective and efficient are the market stewardship initiatives?***

There is a very urgent need for market stewardship in relation to people with complex needs. Otherwise, market failure is quite likely. Initiatives to date appear to be uncoordinated with no clearly informed overarching goals driving investment.

***Is there likely to be a need for a provider of last resort? If so, should it be the NDIA? How would this work?***

History has shown that non-government services regularly find it too difficult to meet complex behavioural needs and withdraw from this role. State government disability services have been the provider of last resort or, putting it more positively, the niche provider in relation to complex behavioural needs. There clearly needs to be such arrangements in the NDIS and we suspect that this may require block funding of providers of last resort who cannot withdraw from service provision to an individual.

## **PAYING FOR THE NDIS**

*[Does the current funding split between the Commonwealth and the States and Territories have implications for the scheme's sustainability? Does it affect the NDIA's capacity to deliver disability care to scheme participants at the lowest cost? Are there any changes that could be made to the funding split that would either improve the financial sustainability or the efficiency of the scheme?]*

*[What proportion of a state or territory's contribution to the NDIS are in-kind services? Are there risks associated with in-kind service contributions?]*

*[What are the implications of the current risk sharing arrangements? Do they encourage either cost shifting or overruns? What, if any, improvements could be made to the current risk sharing arrangements?]*

*[How is the 3.5 per cent increase in a state or territory's contribution to the full scheme calculated? Is this reasonable? Will it skew the balance of the funding over time? If so, what are the implications? Is there a better way to index contributions?]*

*[How will Western Australia's agreement with the Commonwealth Government affect scheme costs?]*

*[Is there a better way of paying for the NDIS? For example, would it be better to fully fund the NDIS out of general revenue?]*

## **Towards a financially sustainable future**

*[How should the financial sustainability of the NDIS be defined and measured?]*

*[What are the major risks to the scheme's financial sustainability? What insights do the experiences from the trial sites provide on potential risks in the context of financial sustainability? How might the NDIA address these risks?]*

*[Does the NDIA's definition of financial sustainability have implications for its management of risk? Are there risks that are beyond the NDIA's remit?]*

*[How does the NDIA progress from identifying a risk to managing it through changes in the delivery of the scheme? Are there any barriers to the NDIA doing this effectively?]*

*[Are there changes that could be made to improve the NDIA's management of risk? Should more details about the NDIA's risk management practices be publicly available?]*

*[Does funding the NDIA on an annual basis affect its management of risk?]*

*[Are there other ways the scheme could be modified to achieve efficiency gains and reduce costs?]*

*[What are the likely longer-term impacts of any cost overruns? How should any cost overruns be funded?]*