Productivity Commission

National Long Term Care and Support
Draft Report

Response – May 2011

Association for Children with a Disability

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INTRODUCTION

Established 30 years ago, the Association for Children with a Disability is a non-profit community based organisation representing children with a disability and their families living in Victoria. Our current membership includes over 2,000 families.

Statement of Purpose

- To empower parents of children with a disability to be as self-sufficient as possible in advocating on behalf of their child and family.
- To promote and advance the rights of children with a disability and their families.
- To advocate on behalf of children with a disability and their families to ensure the best possible support and services are available.
- To work collaboratively with other organisations to improve the service system for children with a disability and their families.

Guiding Principles

- To be responsive to the needs of children with a disability and their families.
- To provide a professional, quality service.
- To be proactive by raising issues with government and building awareness in the community about the rights of children with a disability and their families.

BACKGROUND

Our Association is pleased to be able to respond to the draft report handed down by the Productivity Commission in February this year. Clearly the gathering of information that has led to the Commission's recommendations have been extensive and for all intents and purposes highlights the inadequacies of the current service systems responsible for supporting people with a disability and their families.

Our Association has adopted the Commission's cameo of Jack, a newborn with a severe disability, as the basis of our thinking around the specifics of addressing the needs of children with a disability and their families and how to best support them over the long term. Our responses will include general observations as well as directly addressing draft recommendations and requests for extra feedback on Chapters 3, 4, 5, 68, 9 and 16.

Cameo 3 – A newborn with a severe disability.

Susan has given birth to a boy called Jack who has a major congenital birth defect, which has led to a profound intellectual and physical disabilities. Jack will not be able to walk or talk, will need a wheelchair as he grows and will require lifelong assistance with personal care, including eating, drinking, bathing and toileting. He has an unknown life expectancy.

Susan contacts the National Disability Insurance Agency to make an appointment with an assessor to discuss Jack's needs. Like all babies in the first two years of their life, Jack's personal care needs will be largely met by his parents. However, Susan and her partner are struggling with the emotional impact of caring for Jack and this is also affecting their other children.

The assessor determines a package of supports for Jack and his family – which is signed off by the NDIA. The packages provides some physiotherapy to improve Jack's "floppiness", counseling for the parents and some respite services so the rest of the family can periodically take some time off together. The NDIA also arranges for an NDIA local case manager to visit and the manager puts the family in contact with a local support group. The parents are also told about the support they will be able to get as Jack grows older, so they know with certainty that they will not be left to manage by themselves.

Susan and Mark choose a local respite service, but they are unreliable and not very empathetic. They tell the NDIA and using the information it provides, choose another respite service that has a good reputation for families in their circumstances.

The following table compares support available to Jack and his family, via the Commission's assessment through the NDIS, with what programs currently exist in Victoria to support Jack and his family. The inability of these programs to adequately provide support is well documented, but does not alter the fact that they do exist.

Proposed **NDIS Support**	**Current** **Disability Specific Support - Victoria**
1. **Physiotherapy** 2. **Counseling** for parents 3. **Respite /** Information on alternate respite provider 4. **Information** on support group	1. **Income support** - carer payment/allowance 2. **Occupational therapy** (play therapy) 3. **Speech therapy** (communication feeding, swallowing – Saliva Centre) 4. **Physiotherapy** (seating, muscular skeletal) 5. **Family Support** Program referral 6. **Early Choices** package of services 7. **Aids and Equipment** (bath chair, specialized seating) 8. **Home and Community Care** – personal care support 9. **Commonwealth Carer Respite** Centre 10. **National Carer Counseling** Program 11. **MyTime** group

Determining eligible for inclusion in the NDIS will need to factor in family circumstances. Jack may have other siblings, who may have some health related issues and may or may not have extended family available to support Susan and Mark. Undertaking an assessment solely based on Jack's needs would grossly underestimate the level of support required to assist him and his family. Family circumstances for children tend to have greater variability - greater care load with younger children, higher financial responsibilities with mortgage repayments, cost of education and the primary income earner usually in the early stages of establishing a career pathway.

GENERAL OBSERVATIONS

Family Circumstances

The draft report has a strong focus on people with a disability which does not appear to take into account the different circumstances in which children with a disability 0 to 18 years find themselves and the legal and moral responsibilities families carry in supporting them. It is important for person centred approaches that recognise the needs of children and the rights of parents also recognise the extra responsibilities caring for a child with a disability entails. To assume that support for a young child with a disability equates to the usual level of care provided to a child without a disability, drastically underestimates the reality for the thousands of families we have supported over many many years.

Early Intervention

Our original submission to the Commission highlighted the importance of early childhood intervention. We stated that “When appropriately supported in the early years many of the challenges children face could be either eliminated or reduced by the time they reach adulthood. Overwhelming evidence in recent years confirms broad practice wisdom that early intervention works, providing the best opportunity for children to realise their full potential and dramatically reduces the level of support required over the long term. It makes sound economic sense.” Although providing early intervention through the NDIS may pose challenges due to the nature of the developmental delays young children are experiencing, a focus on the long term benefits must be the primary guide for eligibility. Early diagnosis can be complex and confirmation often takes months an sometimes years, even when symptoms are clearly evident. In these circumstances it will be important that assessment for the NDIS does not get bogged down in securing diagnostic evidence, whilst the ‘clock is ticking’ and opportunities to benefit from early intervention are quickly fading.

Universal Services

The three tier system our Association believes, overestimates the capacity to universal services to support the needs of people with a disability and their families. If people currently receiving support through disability funded services are not deemed eligible for Tier 3 funding in the NDIS and universal services will be expected to pick up the difference, they will need to be adequately funding to absorb the extra demand for support.

Independent Advocacy

Our Association understands that during the Commission’s recent discussions with the disability and carer sectors and presentation to the public hearings, the importance of the role of independent advocacy has been raised. Our Association supports the view that the manner in which the draft report has defined the role of advocacy within the NDIS is grossly inadequate. The central focus of disability advocacy is the person with a disability and their family and exists to promote their rights to be treated as equal citizens in Australia society.

Additionally Australia is a signatory to the UN Convention on the Rights of Persons with a Disability. Advocacy within the NDIS context is aimed at facilitating access to quality disability support only, which falls far short of Australia's responsibilities under the Convention. Our Association also endorses submissions by the Disability Advocacy Network Australia, the Victorian Disability Advocacy Network and Children with Disability Australia in relation to this matter.

DRAFT RECOMMENDATIONS

In response to the Commission's request for feedback on recommendations from the draft report, our Association offers the following reflections -

CHAPTER 3 WHO IS THE NDIS FOR?

Draft Recommendation 3.1

Our Association is concerned with the Commission's assumption that people ineligible for Tier 3, will have their needs met through Tier 2. Evidence over the years demonstrates that universal services neither understand nor adequately meet the needs of people with a disability. To expect that the 4 million people with a disability identified by the Commission as being supported through Tier 2, will be properly supported in this manner is unrealistic. Tier 2 providers are generally under-skilled in disability related expertise. People with a disability and their families will be left to muddle through, expending copious amounts of time and energy searching for the right service to provide the right support.

In relation to Tier 3, Our Association questions the rationale to separately identifying 'intellectual disability' in (3b) and why the Commission does not consider it appropriate to identify 'cognitive capacity' as a core activity limitation.

Draft Recommendation 3.2

Generally this recommendation is supported by our Association, with the inclusion in the first instance, to determine the level of individual need within the family environment and the resultant demand on 'natural supports' as a key component to assess eligibility. This would also trigger consideration as to whether a family carer may require a separate assessment for NDIS.

Draft Recommendation 3.3

Our Association agrees with this Recommendation.

Draft Recommendation 3.4

The interface between disability and primary, secondary and tertiary education would benefit from a memorandum of understanding, along with those identified in this Recommendation, i.e. health, mental health, aged and palliative care.

Draft Recommendation 3.6

Acknowledgement by the Commission that NDIS once operational, should be available to all eligible individuals irrespective of when they acquired their disability, is considered by our Association to be an equitable response.

Draft Recommendation 3.7

Our Association wishes to first clarify the Commission's intent that current need for service or current service use and an assessment of projected future need, is the basis of all assessment processes. If so, then examples of other factors to take into account should be changes in the consumer price index, inflation, etc. If these are included in this draft recommendation, then our Association is in agreement.

CHAPTER 4 WHAT INDIVIDUALISED SUPPORTS WILL THE NDIS FUND?

Draft Recommendation 4.1

Our Association supports this Recommendation, although the strength of such mechanisms is not so much in their existence but rather in their implementation and the knowledge of service users to retain quality supports. We also recommend that NDIS actively seeks to ensure that people with a disability, especially those with a decision-making impairment and their families are aware of and have access to training to improve their negotiation skills so that they can effectively oversee the supports they engage.

Draft Recommendation 4.2

Our Association supports this Recommendation.

Draft Recommendation 4.3

The importance of managing demand for access to NDIS is recognised however as in circumstances where children are born with a congenital disability, families would not be able to demonstrate that they had already contributed significantly towards the cost of support through unpaid care. Waiving the up front contributions for young families is recommended by our Association.

Draft Recommendation 4.4

Our Association agrees that families inevitably have a choice to pursue therapeutic interventions if they have the financial means and desire to do so. NDIS research should include the ongoing evaluation of new and innovative approaches to aids and equipment and therapeutic interventions.

Draft Recommendation 4.5

As with our original submission to the Commission, our Association is of the opinion that Mental Health should not be included in NDIS and continue to be covered by the health sector. If a person's primary need relates to disability and they also have a mental health issue, then clinical support for mental health should remain with the health sector and other supports would be covered by NDIS because of their disability related need.

CHAPTER 5 ASSESSING CARE AND SUPPORT NEEDS

Draft Recommendation 5.1

The need to rely on natural supports from family and friends, should be a component of the assessment process to determine a realistic measure of such capacity. This is particularly true for children with a disability as the intensity of care demands on young families raising all their children is usually higher. In this way the Commission's statement "5.9 … the current disability system places an unreasonable reliance on family carers and one objective of the NDIS is to change that imbalance" will more likely be addressed.

Draft Recommendation 5.2

Quality assessment is the key to quality outcomes and brings with it the challenge of ensuring that the process at an individual and family level balances need with capacity to support. Our Association agrees in principle with the proposed assessment process, however when determining the involvement of 'natural supports' it will be important to evaluate how such support would impact on the financial, physical health and emotional wellbeing of family carers. If families feel that the impact is unreasonable then reliance on 'natural supports' in such circumstances would be inappropriate. Using 'reasonable' as a key determinant in assessing need must focus on outcomes deemed in the best interest of the child with a disability and their family and should not be driven by service capacity.

Additionally, the focus of assessment needs to be age appropriate and include current medical information, therapeutic interventions and allied health support.

Draft Recommendation 5.3

Our Association agrees in principle that tools used to assess need should exhibit a high degree of validity and reliability.

Draft Recommendation 5.4

As previously stated our Association would like to reiterate our concern that the fact an assessor may be familiar with an individual either applying to NDIS or requiring a review of current supports, is seen as jeopardising the validity of the process. Such assessments and re-assessments are not black and white and obtaining a deep understanding of the ever changing needs of a child with a disability, their abilities, aspirations, needs, and realistic levels of natural supports, will not best be served by exclusively engaging an assessor unfamiliar with the applicant/applicant's circumstances. In an effort to avoid

Draft Recommendation 5.4

“sympathetic bracket creep” critical elements of a person’s circumstances can be overlooked or misunderstood and familiarisation that needs to occur to determine an accurate assessment of reasonable need, will take longer. Families are tired of having to tell their children’s story over and over again which our Association suggests would be the unintended consequence of this draft recommendation.

Draft Recommendation 5.5

Our Association supports draft recommendation 5.5 with the added option that children with a disability and their families can instigate a re-assessment if and when their needs change. This is particularly relevant with the pace of child development and the frequency of changes to young family environments.

We also urge the Commission to consider an alignment with other key re-assessment processes that children with a disability and families are involved in e.g. Centrelink review cycles.

Draft Recommendation 5.6

Assessing the support needs of parents is critical to their long term capacity to care for their child with a disability, whatever their biological age. Supports that need to be taken into account include preventative health activities, equipment, respite that also recognises longevity of care and other carer supports and initiatives that would assist parents to continue participating in the workforce.

Draft Recommendation 5.7

This ‘toolbox’ will be the key to whether NDIS provides a better model of support than that already available across Australia. Our Association recommends a rigorous examination (nationally and internationally) of relevant assessment tools to ensure that the depth and breadth of need is accurately captured and appropriately addressed.

Draft Recommendation 5.8

Our Association supports this draft recommendation, with ongoing monitoring having a focus on what might not be adequately captured through eligibility, assessment and re-assessment processes.

Draft Recommendation 5.9

Naturally our Association supports this draft recommendation

CHAPTER 6 WHO HAS THE DECISION-MAKING POWER?

Draft Recommendation 6.1

Capacity to make appropriate choices needs to be factored into this draft recommendation. If people with a disability require support to make appropriate choices, then such support needs to effective. Some examples are - assessors and case managers skilled in the use of assistive technology, ASLAN, effective use of interpreters and in the case of cognitive impairment, working with family and supporters to ensure decisions uphold the rights people with a disability.

Draft Recommendation 6.2

Our Association supports the intent of this draft recommendation.

Draft Recommendation 6.3

Our Association supports this draft recommendation, however in the case where an expensive piece of equipment needs to be purchased, an appropriate allocation is made.

Draft Recommendation 6.4

Also include rural and remote locations where access to formal supports is either limited or non-existent.

Draft Recommendation 6.5

Our Association supports this draft recommendation, with the following provisos –

- In an instance where rural and remote locations prohibit access to a reasonable range of appropriate supports is either limited or non-existent.
- Family members should undertake relevant disability related training - Disability Standards, legislation covering human rights, discrimination and least restrictive practices, OH&S.

Draft Recommendation 6.6

Our Association supports this draft recommendation and would like to bring to the Commission's attention that some agencies already currently exist that are eminently capable of supporting people in the practical use of self-directed funding and that they should not be overlooked in the quest to form Disability Service Organisations.

Draft Recommendation 6.7

This draft recommendation is supported by our Association.

Draft Recommendation 6.8

Our Association would be concerned if "reducing the risks of neglect or mistreatment" by "giving users the capacity to complain……" was the full extent to which people with a disability and their families would be supported. Information and support to lodge a complaint is recommended.

Draft Recommendation 6.9

Our Association supports the intent of the draft recommendation however the early compassionate release of eligible superannuation for disability related purposes should be available to people with a disability as well as family members who support them.

CHAPTER 7 GOVERNANCE OF THE NDIS

Draft Recommendation 7.1

Our Association can see the benefits of having one national independent statutory authority to oversee the administration of NDIS. Assessment and case management along with other service delivery components should sit outside of NDIA.

Draft Recommendation 7.1 (cont)

Conflict of interest would be reduced which would also validate the independence of complaints handling processes.

Draft Recommendation 7.2

Board composition must also include a range of expertise beyond those primarily dedicated to the financial management sector such as, human development, disability, carer support, education and employment, social inclusion.

Draft Recommendation 7.3

Our Association rejects the approach that the role people with a disability and carers in governing NDIS should be restricted to council bodies whose role is to provide advice. This draft recommendation fails to recognise the value of those who live the experience to hold the role of decision makers, rather than mere advisors.

Draft Recommendation 7.4

This draft recommendation is supported by our Association.

Draft Recommendation 7.5

Our Association supports the intent of this draft recommendation.

Draft Recommendation 7.6

Our Association also supports this draft recommendation.

Draft Recommendation 7.7

Monitoring performance needs to include quality. If Treasury has sole carriage of this monitoring role then performance indicators beyond cost effectiveness/productivity is crucial when some people with a disability in receipt of NDIS are vulnerable to exploitation. Our Association believes that this draft recommendation requires further consideration as to whether Treasury is the only appropriate body to be monitoring quality of the NDIS –

Draft Recommendation 7.7 (cont)
assessment, service delivery and outcomes for people with a disability and their families.

Draft Recommendation 7.8
Our Association supports the intent of this draft recommendation with the added requirement to act upon and report on findings within a specified time.

Draft Recommendation 7.9
Apples need to be compared with apples. Our Association recommends that in determining what would be “comparable corporate entities”, quality of life and realising aspirations are a primary focus of such corporate entities.

Draft Recommendation 7.10
Our Association supports this draft recommendation.

Draft Recommendation 7.11
We recognise that a cornerstone to achieving long term sustainability of NDIS lies in its capacity to be financially viable, however the scheme’s positive descriptors must be supported by a structure based on needs rather than the capacity of the service system to deliver. Otherwise in 2018 people with a disability and their families will be still fighting the same battles, cobbling together bits and pieces of a support to just get by.

Draft Recommendation 7.12
Our Association supports the intent of this draft recommendation. Internal complaints mechanisms have proven time and time again to be inadequate. This is where the skill of assessors and the effectiveness of the process to capture the true extent of a person’s needs whether they are a child or person with a disability or their family member, is critical. Therefore merit should be a valid basis on which to lodge an appeal.

CHAPTER 8 DELIVERING DISABILITY SERVICES

Draft Recommendation 8.1
The intent of this draft recommendation is supported by our Association. Experience has demonstrated that when a person (particularly a child) receives a diagnosis and dependent upon of its severity, complexity and uniqueness, they and they families need a broad range of supports. Expertise in providing support at this time should be an absolute priority to the NDIS.

Draft Recommendation 8.2
Comprehensive data collection that is used effectively will enhance the efficacy of NDIS and provide a more seamless engagement for people with a disability and their families. Privacy and confidentiality measures of course are also of paramount importance.

Draft Recommendation 8.3

Our Association supports the intent of this draft recommendation. When the predictor of quality is based on a market driven approach and the consumer/service user belongs to a vulnerable group within society constantly at risk of exploitation, the likelihood of disregard, maltreatment or neglect is high. We cannot stress enough, the need for and importance of robust and independent quality control.

CHAPTER 9 DISABILITY WITHIN THE INDIGENOUS COMMUNITY

Draft Recommendation 9.1

The intent of this draft recommendation is supported by our Association and we particularly urge governments to always work in partnership with aboriginal communities to develop and implement initiatives for people with a disability and their families.

CHAPTER 10 COLLECTING AND USING DATA UNDER THE NDIS

Draft Recommendation 10.1

Our Association supports the intent of this draft recommendation.

Draft Recommendation 10.2

This draft recommendation is also supported by our Association and we refer to our previous point that new and innovative equipment and therapeutic interventions should be an ongoing priority for the research agenda.

Draft Recommendation 10.3

Our Association supports this draft recommendation.

Draft Recommendation 10.4

Our Association also supports this draft recommendation.

CHAPTER 11 EARLY INTERVENTION

Draft Recommendation 11.1

Our Association is concerned with the Commission’s inference that ‘early intervention’ should be assessed on ‘the likelihood of cost-effectiveness’ will compromise access to evidence-based effective therapeutic interventions. Our original submission to the Commission advocated for a system that should not be driven by service capacity but by the expressed needs of those using the Scheme. We are mindful of the fact that some therapies are expensive and highly intensive, however their proven effectiveness should be the basis for their inclusion in the NDIS or NIIS.

All early intervention supports for children with a disability, should be included in an NDIS. Evidence demonstrates that the provision of early intervention when it is needed, has the greatest potential for success. The long term financial benefits of early intervention are undisputed.

CHAPTER 12 WHERE SHOULD THE MONEY COME FROM? FINANCING THE NDIS

Draft Recommendation 12.1

This draft recommendation is not our Association's preferred funding option and therefore we do not support it.

Draft Recommendation 12.2

Our Association supports this draft recommendation as the preferred funding option.

Draft Recommendation 12.3

Our Association supports the intent of this draft recommendation and agrees with the Commission that 12.3(a) currently demonstrates the most merit.

CHAPTER 13 WORKFORCE ISSUES

Draft Recommendation 13.1

As a signatory to the UN Convention on rights of persons with disabilities, it will be important to ensure that an immigration program to address workforce shortages includes mandatory diversity training for its participants. Workers arriving from other countries particularly where a different approach to supporting people with a disability exists, will need more intense induction. Upholding the rights of people using NDIS by adhering to the principles of dignity, respect equality of opportunity and self-determination must be understood and followed by the whole NDIS workforce.

Draft Recommendation 13.2

Our Association supports the intent of this draft recommendation, however suggests that the Working with Children Check regulations currently existing in Victoria be included as an added security for children.

Draft Recommendation 13.3

Our Association is delighted to see this recommendation included in the Draft Report.   As outlined in 5.2 the range of supports that would contribute to families sustaining their caring role extend beyond counselling, and support should include initiatives that individual families believe we best suit their needs. Behaviour management support, respite and socialisation opportunities, therapeutic support such as deep tissue massage, hydrotherapy, equipment to assist with caring role to name a few.

Draft Recommendation 13.4

Our Association supports this draft recommendation.

CHAPTER 16 A NATIONAL INJURY INSURANCE SCHEME (NIIS)

Our Association supports the intent of all Chapter 16 draft recommendations in recognition that the diversity currently existing across the range of compensable schemes requires significant re-calibration to align with an NDIS.

CHAPTER 17 IMPLEMENTATION

Our Association supports the intention of all Chapter 17 draft recommendations in recognition of the challenges establishing such a paradigm shift in the manner in which disability services are provided across Australia.

We also recommend that all jurisdictions continue to be held accountable for their current responsibilities to people with a disability and their families, while the transition process rolls out.

REQUEST FOR FURTHER INFORMATION

Chapter 3 - Mental health

Two systems currently operate in Australia – disability and mental health across all jurisdictions. It is our Association's view that when primary impairment to daily function has been identified as mental health, the support should be the responsibility of the Mental Health Sector. Inadequacies in that system cannot be expected to be addressed by the disability service system per se. If a person has a disability that of itself deems eligibility for NDIS and also has a secondary mental health condition, then clinical support relating to their mental health, should be provided by the Mental Health Sector.

Chapter 4 - Aids and equipment

It is our Association's position that NDIS should cover aids and equipment that constitute an external support such as artificial limbs and cochlear implants.

- Cost of utilities

Higher electricity costs directly due to a person's disability, such as the need to maintain consistent room temperature, use of electrical equipment, daily washing of bedlinen etc need to be covered and included in the individual package of support provided through the NDIS.

- Taxi transportation

The positive elements of the Victorian Multi-purpose Taxi program should be examined as a comparative program to consider for the NDIS

Chapter 4 (cont)

- Income support

As the purpose of the Mobility Allowance is to support people with a disability to access education and employment opportunities, our Association is of the opinion that it should be included in the NDIS as a component of an individual support package. Conversely Carer Payment, Carer Supplement and Carer Allowance are income support payments and as such should remain with Centrelink. These allowances also attract utility concessions which are a substantial assistance to people with a disability and their families meeting their daily living expenses.

Chapter 5 - Assessment

Please refer to our Association's response above.

Chapter 8 - Monitoring service quality

Our Association favours the maintenance of accreditation to deliver disability related support services through regular independent auditing processes to ensure quality is maintained. Where it is determined that a person with a disability engages and manages their own support workers, they will also carry the responsibility for the quality of service provided.

Chapter 9 - Aboriginal communities

Recognition of disability within Aboriginal communities is a major challenge as are many health related issues. Our Association recommends that the primary response to supporting Aboriginal communities should be self-determination however the whole disability service system needs to have the capacity to address the needs of all eligible individuals.

CONCLUSION

Our Association is available if the Commission requires clarification of any elements of this submission.

Elizabeth McGarry
Chief Executive Officer