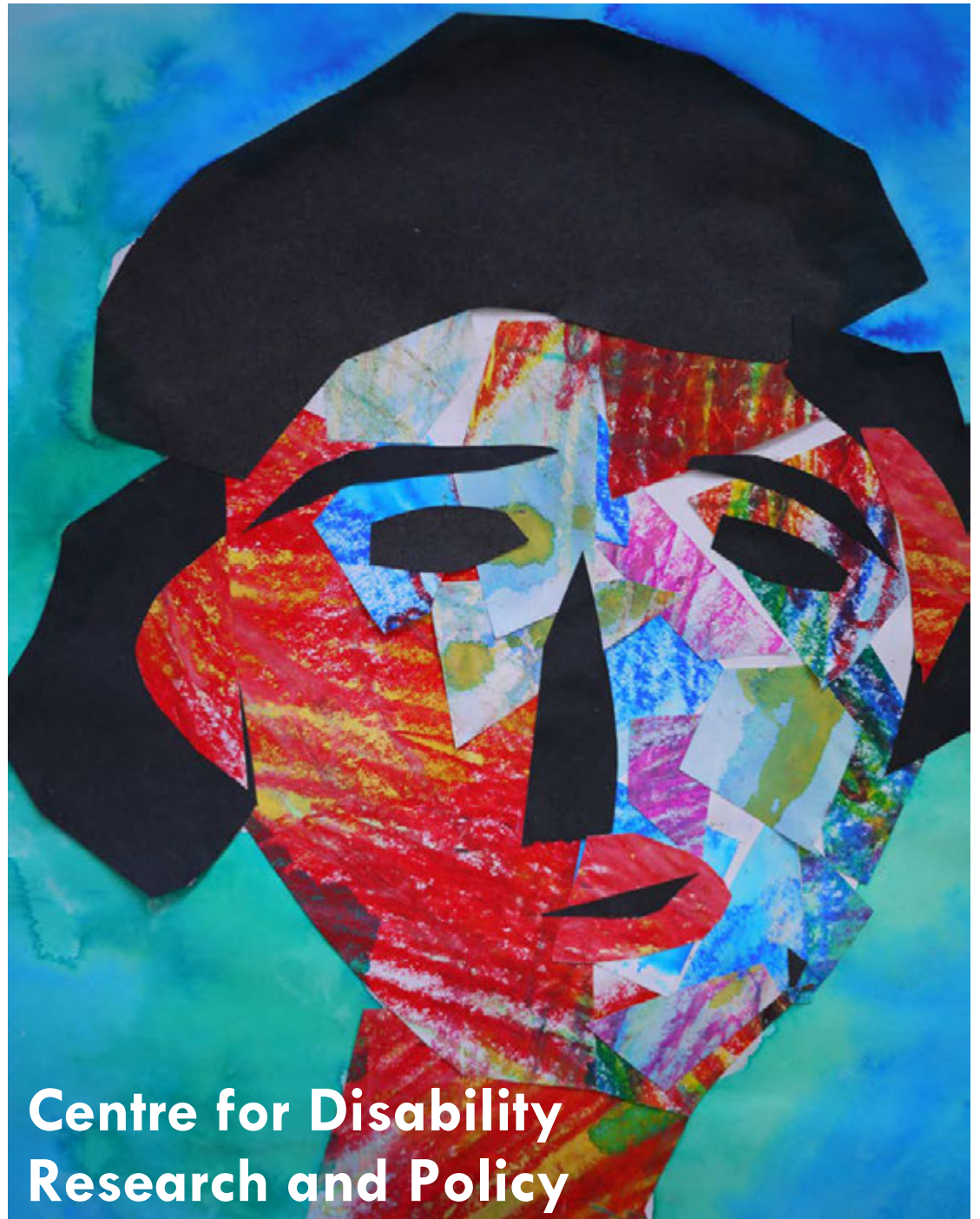




THE UNIVERSITY OF
SYDNEY

Submission re Section 6 Governance and Administration

National Disability Insurance Scheme (NDIS) Costs
Productivity Commission Submission



**Centre for Disability
Research and Policy**

Submission

National Disability Insurance Scheme (NDIS) Costs Productivity Commission

24th March 2017

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Introduction

This submission is about **Section 6 Governance and administration** of the NDIS Issues Paper. Specifically, the submission addresses the recently released *NDIS Quality and Safeguarding Framework* (Department of Social Services, December 9th, 2016)¹ as part of NDIS Governance and Administration. The Foreword to the *Framework* states:

“The Disability Reform Council (DRC) is pleased to release the National Disability Insurance Scheme (NDIS) Quality and Safeguarding Framework. The Framework is designed to ensure high quality supports and safe environments for all NDIS participants. It seeks to help participants and providers access information and resolve issues quickly, and strengthen the capability of participants, the workforce and providers to participate in the NDIS market” (p.4).

The release of the *Framework* was particularly welcome. As noted in the *Framework* document, the state and territory quality and safeguarding arrangements currently in place, remain until full rollout of the NDIS. That said, concerns have been raised since the inception of the trial sites about adequate quality and safeguarding for NDIS participants and specifically in relation to children and young people². This is due to firstly the specific vulnerability of children and young people with disability to maltreatment of all kinds³; secondly, the acknowledged shortfall in current quality and safeguarding arrangements for children and young people with disability around Australia⁴, and thirdly, additional concerns emerging in relation to a market approach to delivery of supports for people with disability including children and young people⁵.

The information provided in this submission draws on our research⁶ conducted for the Royal Commission into Institutional Responses to Child Sexual Abuse. This research examined historical and current perspectives and discourses about children with disability, prevalence of sexual abuse, appropriate mechanisms to ensure high quality supports and safe environments for children with disability in Australia. Other work conducted for the Royal Commission by Dr Sally Robinson investigated the perspectives of children with disability on what constitutes a safe environment⁷. Additional information can be sourced by referring to Case Study 41 of

¹ *NDIS Quality and Safeguarding Framework* 9th December 2016, Department of Social Services released February 3rd 2017 at <https://www.dss.gov.au/disability-and-carers/programs-services/for-people-with-disability/ndis-quality-and-safeguarding-framework>

² Department of Social Services (August 2015) *National Disability Insurance Scheme Quality and Safeguarding Framework. Consultation Report*. ARTD Consultants at https://engage.dss.gov.au/wp-content/uploads/2015/11/consultation_report_ndis_quality_safeguarding_framework.pdfcontent/uploads/2015/11/consultation_report_ndis_quality_safeguarding_framework.pdf

³ Jones, L, Bellis, MA, Wood, S, Hughes, K, McCoy, E, Eckley, L, Bates, G, Mikton, C, Shakespeare, T & Officer, A (2012) Prevalence and risk of violence against children with disabilities: A systematic review and meta-analysis of observational studies, *The Lancet*, 380(9845): 899-907.

⁴ Commonwealth of Australia (2015) *Violence, abuse and neglect against people with disability in institutional and residential settings, including the gender and age related dimensions, and the particular situation of Aboriginal and Torres Strait Islander people with disability, and culturally and linguistically diverse people with disability*. Senate Community Affairs Committee Secretariat, Canberra, ACT, Available at: http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Violence_abuse_neglect/Report

⁵ Carey, G., Kavanagh, A., & Llewellyn, G. (under review). Redressing or entrenching social and health inequities through policy implementation? Examining personalised budgets through the Australian National Disability Insurance Scheme, *Health Promotion International*

⁶ Llewellyn, G., Wayland, S., & Hindmarsh, G. (November 2016). *Disability and child sexual abuse in institutional contexts*. Royal Commission into Institutional Responses to Child Sexual Abuse, Sydney.

⁷ Robinson, S. (February 2016). *Feeling safe, being safe: What is important to children and young people with disability and high support needs about safety in institutional settings*. Royal Commission into Institutional Responses to Child Sexual Abuse, Sydney.

the Royal Commission conducted in July 2016⁸ and Case Study 57 to be conducted in the week beginning March 27th 2017⁹.

Section 6 Governance and administration of the NDIS

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

The NDIS is predicated on maximising the participation of people with disability in the community and through participation, achieving their goals. This is significant social policy reform which requires acceptance of, and support for people with disability from the community as documented in the *National Disability Strategy 2010-2020*¹⁰. To ensure quality and safeguards in a market based system for people with disability is new policy and programming territory in Australia¹¹.

There is an aggregation of vulnerabilities from being a child and from having a disability¹². It could be expected that specific attention would be given to the intersection of childhood and disability in all policy frameworks.

The opposite is the case. As noted in our research report *Disability and Sexual Abuse in Institutional Contexts*, there is a disconnect between the disability children's sectors governance arrangements, national policy frameworks, regulatory mechanisms, and programming initiatives, monitoring and evaluation.

The newly released *NDIS Quality and Safeguarding Framework* almost entirely neglects the particular vulnerability of disabled children. In that document, it is almost as though people with disability are only those who are adults. *The National Framework for Protecting Australia's Children 2009-2020*¹³ and its accompanying Implementation Plans, ignore the particular vulnerabilities of children with disability instead focusing on support for their families. Here it is as if children are rarely disabled.

Neither approach is supported by the evidence.

⁸ Case Study 41, Royal Commission into Institutional Responses to Child Sexual Abuse, Sydney at <http://childabuseroyalcommission.gov.au/case-study/27150f40-1e84-4b27-9f8b-c25fc162a561/case-study-41,-july-2016,-sydney>

⁹ Case Study 57, Royal Commission into Institutional Responses to Child Sexual Abuse, Sydney at <http://childabuseroyalcommission.gov.au/case-study/e341c435-f077-4a98-96eb-8d48779c1d98/case-study-57,-march-2017,-sydney>

¹⁰ Commonwealth of Australia (2011), *2010-2020 National Disability Strategy* An initiative of the Council of Australian Governments, Available at:

https://www.coag.gov.au/sites/default/files/national_disability_strategy_2010-2020.pdf

¹¹ Department of Social Services (August 2015) op.cit

¹² Llewellyn et al (November 2016) op.cit

¹³ Commonwealth of Australia (2009). *Protecting children is everyone's business. National framework for protecting Australia's children 2009-2020*. An initiative of the Council of Australian Governments at <https://www.dss.gov.au/our-responsibilities/families-and-children/publications-articles/protecting-children-is-everyones-business>

In June 2012, the ABS produced *Australian Social Trends June 2012: Children with a disability* based on data from the ABS in the 2003 and 2009 SDAC. For the first time, the ABS reported the proportion of children with disability (0-14 years) in the general population averaging at 6.1 per cent (3.4 per cent in 0-4 age range and 8.8 per cent in 5-14 age range, ABS, 2012). Of the four million Australians in 2009 who had a disability, 290,000 (7.2 per cent) were children aged 0-14 years¹⁴.

There is approximately 6% of the Australian population who are children with disability (up to 14 years) who are inadequately protected. The international evidence demonstrates that children with disability are nearly 3 times more likely to be sexually abused than their non-disabled peers¹⁵. Recently published research from Western Australia reports similar increased prevalence ratios for other types of maltreatment of children with disability¹⁶.

The *NDIS Quality and Safeguarding Framework* relies heavily on regulatory mechanisms to protect children such as the *Working with Children Check* and market based mechanisms which demand informed consumers and/ or consumer support. These are unlikely to be adequate for many children with disability who, in Australia as elsewhere, are proportionally over-represented in care and protection proceedings and out-of-home care^{17,18}.

There is tragic irony in understanding that children with disability are at a heightened risk of violence and abuse yet national legislation and regulatory and policy frameworks are virtually silent on their protection. There are many reasons why children with disability have been so neglected in policy including attitudes toward disability, segregation and institutionalisation even when the children are in a community setting such as mainstream schooling, or assuming that the community takes care of its most vulnerable. None of these reasons should not continue as excuses for inaction towards this significant proportion of the NDIS participant population.

Can these arrangements be improved?

The NDIS Early Childhood Early Intervention (ECEI) approach.

“The ECEI approach is designed to be a ‘gateway’ to the NDIS for children aged 0 to 6 years old. It aims to ensure that only those children who meet the eligibility criteria of the NDIS become participants of the scheme. Under the ECEI approach, families meet with an early childhood intervention service provider to discuss the needs of their child. The provider then identifies

¹⁴ Australian Bureau of Statistics (2012) *Children with a disability*, Catalogue No.4102.0. ABS Canberra, Available at:

<http://www.abs.gov.au/AUSSTATS/abs@.nsf/allprimarymainfeatures/E0094F4770CFB2A0CA257A840015FA3D?opendocument>

¹⁵ Jones et al. (2012) op.cit

¹⁶ Maclean, M.J., Sims, S., Bower, C., Leonard, H., Stanley, F. J., & O'Donnell, M. (online March 6 2017). Maltreatment risk among children with disabilities. *Pediatrics*, 139 (4), e20161817

¹⁷ Ombudsman NSW, n.d. Disability reportable incidents.

<https://www.ombo.nsw.gov.au/what-we-do/our-work/community-and-disability-services/part-3c-reportable-incidents>

¹⁸ Ombudsman NSW (2016) *Disability Section 16 years of Reportable Conduct Forum. What have we learnt and where are we heading February 26 2016*. Ombudsman NSW, Sydney, Available at: <https://www.ombo.nsw.gov.au/training-workshops-and-events/community-education-events-and-forums/reportable-conduct-forum/reportable-conduct-forum>

appropriate supports for the child and family, and whether the supports should be provided through the NDIS or through mainstream services.

The ECEI approach is being implemented in line with the full rollout of the NDIS¹⁹.

The ECEI is one measure taken by the NDIA to manage costs¹⁸. This 'gateway' approach inevitably 'streams out' a proportion of children who are not NDIS participants. These children are streamed into mainstream services. Mainstream services by definition do not offer early intervention specialist support services. If parents attempt to find early intervention specialist services they discover that, previously funded by state or territory, these services no longer exist. Mainstream services are their only option.

When previously available early intervention specialist services are provided for NDIS participants this is reasonable one-for-one equivalence. When children who were previously eligible for early intervention specialist services no longer receive these, it is not reasonable. The gateway approach with young children is inherently risky. There is no robust evidence to support 'cut-off' decisions made between children coming into the NDIS (and receiving specialist supports) and those streamed into mainstream services. There is research to support the effectiveness of dedicated early intervention specialist services²⁰. What is not known is what happens to children with a disability who do not receive these.

There are five issues each of which has a solution.

1. *The first is NDIS data being made publically available on all young children in the 0-6 age range to examine the 'cut-off' process and the trajectories of children accepted into the NDIS compared to those 'streamed out'. This data must be examined by independent third party researchers to determine whether the cut-off criteria are reliable, valid and able to predict the best possible child outcomes.*
2. *The second is to redress the current situation of children not receiving early intervention specialist services. The state/ territories need to be the provider of last resort. The NDIS is good social policy predicated on 'intervene'/ support early to maximise participation. The NDIS ECEI Approach makes clear it is not able to fulfil this promise for all young children with disability. The NDIS ECEI Approach is predicated on solid evidence that early intervention specialist services are effective in minimising disability, increasing functioning and giving young children with disability the best start in life. The state has a responsibility to ensure that evidence based early intervention is available to young children with a disability who are 'streamed out' into mainstream services.*
3. *NDIS documentation is needed on NDIA governance and responsibility for child safe environments for young children 0-6 years at all levels of the NDIS: as participants, and in LAC and in ILC. The NDIS ECEI Approach relies heavily on a collaborative and coordinated interface between the NDIS and mainstream services. The logical complement to this is an effective, integrated quality and safeguarding mechanism across sectors²¹. This is not articulated in the NDIS Quality and Safeguarding Framework or the NDIS Early Childhood Intervention (ECEI) Approach, 26th February 2016 documentation. Rather, the Framework focuses on market choice and turns to existing sector specific frameworks and consumer protection mechanisms²². The NDIS ECEI Approach addresses only rationale and process²³.*
4. *NDIS documentation is needed on NDIA governance and responsibility for child safe*

¹⁹ NDIS Early Childhood Early Intervention (ECEI) Approach, 26 February 2016. ndis.gov.au at <https://www.ndis.gov.au/html/sites/default/files/documents/Research/NDIA-ECEI-Approach-1.pdf>

²⁰ For example, as cited in NDIS Early Childhood Early Intervention (ECEI) Approach, 26 February 2016 op.cit

²¹ Llewellyn et al. (2016) op.cit and witness statement to Royal Commission for Institutional Responses to Child Sexual Abuse Case Study 57 (March 2017)

²² NDIS Quality and Safeguarding Framework 9th December 2016 op.cit

²³ NDIS Early Childhood Early Intervention (ECEI) Approach, 26 February 2016 op. cit

environments for older children with disability at all levels of the NDIS: as participants, and in LAC and in ILC. The NDIS ECEI Approach is only applicable to children aged under 6 years and their families. It is highly likely that the number of older child participants in the NDIS at full rollout will mirror the 9% prevalence figures of children with disability (5-14) in the general population. This means that more than half of all NDIS child participants will be 5-14 years of age. At this age, children's daily lives are spent in and across many sectors. This reinforces the need to develop cross-sectoral, integrated quality and safeguarding mechanisms. There are proposed national mechanisms in the NDIS Quality and Safeguarding Framework, however these rely on effective and timely coordination and collaboration with existing state and territory based mechanisms²⁴. There is evidence that children with disability are already disproportionately represented in state based reportable conduct matters schemes²⁵. More older children with disability will be accessing mainstream services only streamed there at a younger age by the NDIS ECEI Approach.

5. *Data must be routinely collected and made publically available. To reduce the heightened risk of maltreatment of children with disability we have to answer the question: which children, to what extent and under what conditions? The data must be disaggregated by age, gender, geographical location, Aboriginal and Torres Strait Islander children and culturally and linguistically diverse background, functioning status and NDIS supports. This is critical for trend analysis and evaluation of the effectiveness (or otherwise) of the NDIS quality and safeguarding mechanisms. It is also critical to guide evidence-informed corrective action, if needed, to NDIS governance and administration. The data must be available for independent third party researchers rather than relying on in-house evaluation.*

Children with disability are Australia's future citizens. Their development and progress during childhood are critical to containment of costs and NDIS sustainability in future years. This point alone ought to direct much greater government attention - NDIA, DSS and state and territory governments - than is currently the case to the safety of children with disability in NDIS governance and administration. Only then can we begin to mitigate the known increased risk of maltreatment for children with disability in support and service contexts in Australia.

About the Centre for Disability Research and Policy:

The Centre for Disability Research and Policy (CDRP) at the Faculty of Health Sciences of the University of Sydney aims to change the disadvantage that occurs for people with disabilities. We do this through addressing their social and economic participation in society, and their health and wellbeing. By focusing on data that demonstrates disadvantage, we can develop models of policy and practice to better enable support and opportunity for people with disabilities.

Dr Gwynnyth Llewellyn is Professor of Family and Disability Studies at the University of Sydney; Director, Centre for Disability Research and Policy; and, Head, WHO Collaborating Centre on Health Workforce Development in Rehabilitation and Long Term Care. She also leads Healthy Sydney University, a cross institutional policy initiative to build a health promoting culture and environment for students, staff and visitors in the university.

²⁴ NDIS Quality and Safeguarding Framework 9th December 2016 op. cit

²⁵ Ombudsman NSW (2016) *Disability Section 16 years of Reportable Conduct Forum. What have we learnt and where are we heading February 26 2016*. Ombudsman NSW, Sydney, Available at: <https://www.ombo.nsw.gov.au/training-workshops-and-events/community-education,-events-and-forums/reportable-conduct-forum-/reportable-conduct- forum->

Her research addresses disability and inequities and effective policy solutions to reduce health inequalities. In this capacity, she co-leads the National Medical Health and Research Council Centre of Research Excellence – Disability and Health. Her published work spans several decades of research endeavours in the field of parents with disabilities and their families; the experiences of children and young people with disability maltreatment; disability and discrimination particularly in public places; and disability inclusive disaster risk reduction policies and practices.

Her work for WHO includes policy and planning in disability inclusive national strategies, rehabilitation in universal health care, capacity building in the rehabilitation workforce and community based inclusive development in the South East Asian and Pacific regions. She currently serves as Expert Advisor on Disability to the Royal Commission into Institutional Responses to Child Sexual Abuse.