



This is a joint initiative of the Division of Rehabilitation, Metro South Health, Menzies Health Institute Queensland and Griffith University.

## **Submission to the Productivity Commission Issues Paper: National Disability Insurance Scheme (NDIS) Costs**

Members of the Hopkins Centre Research for Rehabilitation and Resilience<sup>1</sup> are pleased to have the opportunity to provide submissions in response to the issues paper on costs of the National Disability Insurance Scheme. Hopkins Centre Research for Rehabilitation and Resilience is committed to improving disability and rehabilitation practices, service delivery and systems by developing, translating and implementing interdisciplinary research evidence about real world problems. The Centre is located at Griffith University, Logan campus and Princess Alexandra Hospital, Metro Health South to facilitate opportunities for research exchange and excellence between clinical experts, practitioner researcher and academics. The Centre focuses on research of relevance to people living with the long-term consequences of acquired brain injury, amputation, persistent pain, and spinal cord injury as well as developmental, age-related and other life-long disabling conditions.

### **Intersection with the National Injury Insurance Scheme<sup>2</sup>**

While NIIS schemes for motor vehicle injuries and work injuries have been introduced across Australia, there has been little progress in the development of NIIS schemes for other injuries including those caused by medical error, recreational injury, criminal injury and general injury. This will cause a cost pressure on the NDIS scheme as those with significant disability from these injury categories seek to enter the NDIS. In addition, the majority of those with catastrophic injury in these categories will not have early and full access to rehabilitation (as they would in a NIIS) which will likely increase the cost burden of their long term care on the NDIS.

In Queensland and Western Australia the Motor Vehicle NIIS schemes allow for claimants with a catastrophic injury who can demonstrate fault to 'cash out' of the relevant state NIIS schemes

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<sup>1</sup> <http://www.hopkinscentre.edu.au/>

<sup>2</sup> Submissions by Dr Kylie Burns, Griffith Law School, K. Burns@griffith.edu.au

by taking a lump sum payment.<sup>3</sup> A proportion (and perhaps a significant proportion) of those who receive a lump sum payment are likely to prematurely dissipate that lump sum. If these claimants then seek to enter the NDIS and are successful in doing so this will place cost pressure on the NDIS. Administrative costs will be caused due to disputes between the States and the Commonwealth in relation to who bears the burden of the NDIS costs of these participants, and potentially in relation to disputes between potential participants and the scheme in relation to scheme entry.<sup>4</sup> Finally, if participants are refused entry to the NDIS due to the receipt of a lump sum which has been dissipated, costs will be transferred to other systems such as the health system. Injured people may also be left destitute- an outcome the NDIS was designed to avoid.

Although the current state of research does not allow an indication of prevalence, it is clear from an examination of Centrelink data and social security preclusion appeals that some compensation recipients prematurely run out of money.<sup>5</sup> Research we have conducted with collaborators from Griffith University, UNSW and Monash University suggests that some compensation claimants may prematurely dissipate compensation payments with significant negative consequences for their health and other outcomes. Many of the reasons for premature dissipation are beyond the control of individual claimants and include excessive legal fees and disbursements; the effect of the 5% discount rate; inadequate calculation of long term medical and care costs; provision of housing; divorce; downturn in financial markets; cognitive impairment; effect of the calculation of social security preclusion periods; and fraud and theft by carers.<sup>6</sup> There is not good existing empirical evidence about what proportion of compensation recipients prematurely dissipate compensation. Available existing data concerns perceptions of adequacy at the time of or close to settlement. The lack of this long term adequacy data presents difficulties to schemes and governments when they review the effectiveness and adequacy of compensation schemes including the NDIS and NIIS. We recommend that data be gathered on the long term outcomes of compensation recipients in relation to compensation adequacy. This will allow data driven review of the NIIS and NDIS schemes in the future.

The initial Productivity Commission Report on Disability Care and Support<sup>7</sup> outlined convincingly the detriments and costs of the fault based system of injury compensation and was critical of the enormous complexity of injury compensation in Australia. This included issues such as high administrative and legal costs; inadequate compensation due to discounting and early settlement and inaccurate long term prediction of care costs; the stressful nature of the

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<sup>3</sup> See National Injury Insurance Scheme (Queensland) Act 2016 (Qld) ss 42–44; Motor Vehicle (Catastrophic Injuries) Act 2016 (WA) ss 5(3), 8(3).

<sup>4</sup> Support under the NDIS may be reduced or refused where a participant can access or has accessed compensation via a compensation claim or through another scheme. See National Disability Insurance Scheme Act 2013 (Cth) Ch 5; National Disability Insurance Scheme (Supports for Participants – Accounting for Compensation) Rules 2013.

<sup>5</sup> In 2014, Centrelink reported that, in 2013-14 there were 692 compensation preclusion appeals dealt with by Centrelink Review Officers (internal review). Senate Community Affairs Legislation Committee, *Supplementary Budget Estimates, 23-24 October 2014 Answer to Question on Notice* (HS 166, 2).

<sup>6</sup> Genevieve Grant, Kylie Burns, Rosamund Harrington, Prue Vines, Elizabeth Kendall and Annick Maujean, 'When Lump Sums Run Out: Disputes at the Borderlines of Tort Law, Injury Compensation and Social Security' in Kit Barker, Karen Fairweather and Ross Grantham, *Private Law in the 21st Century*, Hart, 2017 (Copy available upon request) . See also

<https://www.parliament.qld.gov.au/documents/committees/ETISBC/2016/NIISQBill2016/submissions/006.pdf>;  
<https://www.parliament.qld.gov.au/documents/committees/ETISBC/2016/WorkersComp/submissions/001.pdf> .

<sup>7</sup> Productivity Commission, *Disability Care and Support: Inquiry Report*, Report No 54, Productivity Commission, Canberra, 2011 (NDIS Report), <http://www.pc.gov.au/inquiries/completed/disability-support/report>, Chapter 17.

litigation process; the psychological impact of litigation which impedes the recovery from injury; and the 'lottery' nature of the common law system. The NDIS was seen as part of a response to these inadequacies of the common law system. Given this, the introduction of legislative provisions by which the NDIA may require or mandate common law litigation for injured participants<sup>8</sup> where there may be fault, seem short sighted and likely to increase the overall costs of the scheme rather than 'claw-back' costs from the common law system.<sup>9</sup> There are likely to be detriments to injured participants whereby the litigation may hinder recovery from injury and thereby ultimately increase the costs of care.

### **'Reasonable and Necessary Supports' and Financial Sustainability<sup>10</sup>**

There is an emerging lack of clarity<sup>11</sup> in relation to the whether an individual participant's support that otherwise meets the requirements of the *National Disability Insurance Act* s 34 (1) as a 'reasonable and necessary support' can be refused or only partly funded on the basis that there is a general objective of 'financial sustainability' of the NDIS (s 3 (3)(b)). The refusal or only part-funding of supports which are otherwise considered reasonable and necessary, risks repeating the inefficiencies and deficiencies of previous much criticised disability support schemes. This may also involve false short term economies- for example the refusal to fund or only part-funding of adequate home care may lead to rapid family breakdown requiring more expensive out of home care.

### **Complex Communication Needs<sup>12</sup>**

People with complex communication needs (CCN) rely on the knowledge and skills of others to provide interactional support using non-speech methods of communication such as communication aids, technological communication devices, and sign language/gestural systems. These multi modal and often disability specific approaches are referred to as augmentative and alternative communication (AAC). In order to 'support and build skills and capacity' it is essential that the knowledge and skills of individuals providing AAC support exceeds that of the person with CCN. Research literature informs that there is a long standing and significant shortfall in the capacity of the Australian community to meet the needs of people with CCN.<sup>13</sup> In addition, research shows that the key stakeholder group of speech language pathologists are limited in their confidence and competence to respond to the needs of people with CCN.<sup>14</sup> In

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<sup>8</sup> *National Disability Insurance Act 2013* Chapter 5 Part 1-Part 3.

<sup>9</sup> See H Luntz, 'Compensation Recovery and the National Disability Insurance Scheme' (2013) 20 *TLJ* 153.

<sup>10</sup> Submissions by Dr Kylie Burns, Griffith Law School, K.Burns@griffith.edu.au

<sup>11</sup> For example see *McGarrigle and National Disability Agency* [2016] AATA 498; *JQJT and National Disability Insurance Agency* [2016] AATA 478 (6 July 2016); *PNMJ and National Disability Insurance Agency* [2015] AATA 866 (11 November 2015)

<sup>12</sup> Submissions by Jane Remington-Gurney, Adjunct Research Fellow and PhD candidate, jane.remington-gurney@griffithuni.edu.au.

<sup>13</sup> Koul, R., & Lloyd, L. (1994). Survey of professional preparation in augmentative and alternative communication (AAC) in speech language pathology and special education programs. *Augmentative and Alternative Communication*, 3, 13-22; Ratcliffe, A., & Beukelman, D. (1995). Pre-professional preparation in augmentative and alternative communication: State of the art report. *Augmentative and Alternative Communication*, 11(2), 61-73; Ratcliffe, A., Koul, R., & Lloyd, L. (2008). Preparation in augmentative and alternative communication: An update for speech language pathology training. *American Journal of Speech Language Pathology*, 17(1), 48-59.

<sup>14</sup> Soto, G., Müller, E., Hunt, P., & Goetz, S. L. (2001). Critical issues in the inclusion of students who use augmentative and alternative communication: An educational team perspective. *Augmentative and Alternative*

order to 'enable people to engage equitably in all environments' service standards need to be developed for individuals who provide interaction support. Service standards would aim to provide the means for interactional support to be scaffolded from closed question, and linear acts of communication to the dynamic turn taking exchange process specific to conversation.<sup>15</sup>

The literature advises that there is an unacceptably high incidence of abandonment (as much as 75%) of communication devices in Australia. For many individuals with CCN they are unable to set up, program and maintain their own communication equipment. Consequently, there is arguably a need to provide adequate support to the person with CCN as well as those who assist them.<sup>16</sup>

### *Response to specific questions re CCN*

#### 1. Scheme costs.

- i. It is unclear how sustainable and equitable support will be (a) acquired by support personnel (b) monitored for efficacy and functionality and (c) be accelerated by government processes.
- ii. Are utilisation rates low because consumers and service providers do not have the same awareness of market resources in AAC that can meet the specific needs of people with CCN?

#### 2. Scheme boundaries.

- i. At the early intervention stage there is arguably a greater chance of consumers being introduced to AAC as a member in a multidisciplinary, Participation Model approach.<sup>17</sup> A potential risk is that in the longer term, the impact that AAC can have on quality of life will become evident and potentially generate heightened awareness of need.

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Communication, 17(June).ISAAC Australia. (2014). Prevalence of different types of speech, language and communication disorders and speech pathology services in Australia: Submission 132. (132). Australia

<sup>15</sup> Remington-Gurney, J. (2017), Conversations without speech: A qualitative investigation of the strategies used by adult communication assistants in Queensland. Griffith University, Brisbane, PhD thesis (to press). Trembarth, D., Baladin, S., Stancliffe, R. J., & Togher, L. (2010). "Communication is Everything": The experiences of volunteers who use AAC. *Augmentative and Alternative Communication*, 26(2), 75-86. Togher, L., McDonald, S., Tate, R., Power, E., & Rietdijk, R. (2013). Training communication partners of people with severe traumatic brain injury improves everyday conversations: A multicenter single blind clinical trial. *Journal Rehabilitation Medicine*, 45, 637-645. Blinger, C., & Kent-Walsh, J. (2012). Communication Takes Two. *The ASHA Leader*, December 18.

<sup>16</sup> Baxter, S., Enderby, P., Evans, P., & Judge, S. (2012). Barriers and facilitators to the use of high-technology augmentative and alternative communication devices: A systematic review and qualitative synthesis. *International Journal Language and Communication Disorders*, 47(2), 115-129.

Johnson, J. M., Ingelbert, E. A., Jones, C., & Ray, J. (2006). Perspectives of speech language pathologists regarding success versus abandonment of AAC. *Augmentative and Alternative Communication*, 22(2), 85-99.

<sup>17</sup> Beukelman, D., & Mirenda, R. (1998). *Augmentative and Alternative Communication. Management of severe communication disorders in children and adults*. Baltimore, U.S.A: Brookes.

ii. Is data being gathered to provide new knowledge regarding the AAC awareness of individuals responsible for eligibility assessment processes?

### 3. Planning processes.

i. The visibility of the planning process could be improved with audio-visual and print media illustrations of how AAC has been used to enable the goals, aspirations and objectives of individuals to be realised. Individuals may rely on the support of another person to use technologies such as Talking Mats<sup>18</sup>, Key Word Signing<sup>19</sup> and interpretation of body language. In addition Communication Passports could be constructed to illustrate possibilities. Speech is only one vehicle for thought. It is a human right<sup>20</sup> to access any method of communication even though some will take considerably longer than others.

ii. Monitoring the performance of planners could be achieved with performance standards and mentoring processes. The latter might include E-Learning resources. It would also be desirable to ensure that performance planners were not naïve to AAC. Further, that there be consideration to articulation of interaction support from communication partner (with little or no AAC knowledge and skill), to communication assistant (with some AAC knowledge and skill), to communication coach (with expertise in multimodal AAC and the use of electronic communication devices). Partnerships with universities that provide undergraduate and graduate, AAC training would be advantageous in this process of training, monitoring and evaluating.

### 6. Will the workforce be ready?

i. There is a well-established short fall in the capacity of speech language pathologists (SLP) to meet community need in disability. These allied health professionals are acknowledged in the literature as a key stakeholder group. There needs however, to be greater attention to the role that could be played by individuals who are not SLPs. That is, individuals who have undertaken AAC specific training and have the skills to mentor.

ii. In our professional experience individuals are not well-equipped to interact with the scheme, negotiate plans or locate services.

### 7. Paying for the NDIS.

i. It could be advantageous to have some audio-visual illustrations of how the scheme has been used by some individuals as examples of best practice and questionable practice.

ii. Qualitative and quantitative studies would be one way to measure efficiency and effectiveness of the scheme.

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<sup>18</sup> Murphy, J., & Cameron, L. (2008). The effectiveness of Talking Mats with people with intellectual disability. *British Journal of Learning Disabilities*, 36(4), 232-241. Meuris, K., Maes, B., & Zink, I. (2015).

<sup>19</sup> Key word signing usage in residential and day care programs for adults with intellectual disability. *Journal of Policy and Practice in Intellectual Disabilities*. 11(4), 255-267. doi: 10.1111/ippi.2014.11.issue-4/issuetoc.

<sup>20</sup> Kayess, R., & French, P. (2008). Out of darkness Into light? Introducing the Convention on the Rights of Persons' with Disabilities. *Human Rights and Law Review*, 8(1), 1-34.

Further information illustrating how the NDIS can work with people who have CCN is required to secure them a better quality of life. A picture paints a thousand words, especially in a multicultural and multilingual society. Investment in disability accessible websites, and audio-visual information dissemination that are shared using social media platforms could be an asset for equity and sustainability.

### **ABI (Acquired Brain Injury): Eligibility<sup>21</sup>**

We raise concerns in relation to the eligibility of some people with ABI to access the NDIS. The Issues paper (p 3) refers to the NDIS as for people with ‘profound or severe permanent disability’. However, this has usually been couched as ‘people with a permanent disability that substantially reduces their functional capacity or psychosocial functioning’. The eligibility criteria noted in Figure 3 (p 14) may impact on the ability of some people with ABI to access the scheme. This may, for example, impact people who have made reasonable physical and cognitive recovery but who have marked changes to personality and significant behavioural impairments (including such things as reduced frustration tolerance, aggression, impulsivity, disinhibition, adynamia/ loss of initiation and motivation with resulting high need for prompting / supervision). This would be best described as psychosocial impairment. However, the psychosocial impairment documents produced by the NDIA and NDIS appear to be related exclusively to people with mental health conditions, and in the absence of substantial intellectual, cognitive, neurological, sensory or physical impairments, or a mental health diagnosis, some people with significant ABI are likely to be deemed ineligible. This concern extends to people with impaired insight and a resulting reduction in ability to identify their own support needs.

### **Early Intervention and ECEI<sup>22</sup>**

As noted in Box 1 of the Issues Paper (p 12) the ECEI approach has been adopted in response to cost pressures emerging in the NDIS. It is intended as a ‘gateway’ to the NDIS. We have concerns in relation to the manner in which this approach is being utilised and the evidence base for the ECEI. There is a disconnect between the good practice guidelines commissioned by the federal government<sup>23</sup> and the ECIA guidelines.<sup>24</sup> For example, the ECIA approach seems to encourage parent-mediated interventions when in autism the evidence base is insufficient.<sup>25</sup> In contrast, good practice guidelines suggest a need for 20-25 hours of intensive intervention. The use of therapies which lack evidence base and which are therefore unlikely to provide outcomes, will place unnecessary costs pressure on the NDIS.

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<https://www.ndis.gov.au/html/sites/default/files/Early%20Intervention%20for%20Autism%20research%20report.pdf>

<sup>24</sup> <https://www.ecia.org.au/documents/item/186>. See discussion of the disconnect at

<http://www.a4.org.au/node/1320> ;

[http://www.parliament.vic.gov.au/images/stories/committees/fcdc/inquiries/58th/Autism/Submissions/S052\\_Lizard\\_Centre.pdf](http://www.parliament.vic.gov.au/images/stories/committees/fcdc/inquiries/58th/Autism/Submissions/S052_Lizard_Centre.pdf) .

<sup>25</sup> See Cochrane review:

<http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD009774.pub2/abstract?systemMessage=Wiley+Online+Library+will+be+unavailable+on+Saturday+25th+March+from+07%3A00+GMT+%2F+03%3A00+EDT+%2F+15%3A00+SGT+for+4+hours+for+essential+maintenance.+Apologies+for+the+inconvenience> .

In relation to workforce capacity in this area, issues arise not only in shortfalls of relevant skills, but also due to evidence of the continued use of ineffective practices by professionals. This poses challenges in workforce development. There is a need to ensure that there is professional development in evidence based practices to allow those therapies and treatment that are effective to be distinguished from those which lack any evidence base. This can also raise issues in relation to what can sometimes be a contrast between "choice and control" by a client and use of "evidence based" practice.<sup>26</sup>

### **General Comments re Scheme costs, Planning Process and Workforce Readiness<sup>27</sup>**

- I. Quality of services should be added as potential cost drivers. Delivery of poor quality services which do not respond adequately to the complexity of need of some participants may escalate scheme costs if functional deterioration or collapse of informal support networks occurs.
- II. Commodification of informal care and cost shifting from mainstream services are also likely to increase scheme costs. This is reflected in the in the experience of European lifetime care and support schemes, the increasing privatisation of the allied health workforce in Australia, and may explain increasing package costs over and above the impacts of inflation and aging as people move into their second and third plan.
- III. Greater than expected variability in package costs for participants with similar conditions and levels of function and low plan utilisation rates are indicative of participant education needs. Consultations with Occupational Therapists working within Qld, NSW and Victoria revealed that some participants are not aware of how to organise funded supports or identify appropriate suppliers once they received notification of their plan. Allocation of supports coordination hours within participant plans were seen as vital to assist participants in implementing their plans, as these services cannot be claimed as billable hours by providers of individual support. Previous block funding arrangements provided more flexibility for therapists to assist with supports coordination and identification of services available.
- IV. Consultations with Occupational Therapists and community service providers identified the following issues with the planning process:
  - a. Participants with complex needs require specialist support coordination however this support is often not included in initial plans. Lack of specialist support could cause cost escalation within the scheme if functional deterioration or deterioration in informal support networks occurs.
  - b. Adequate time for trial of complex seating systems is often not included in plans, and not all therapists were aware they could request additional hours for prescription purposes in these cases
  - c. Funding for maintenance and repair of equipment needs to be factored into participant plans.
- V. Supporting the sustainability of informal care through a proactive approach to informing families of mainstream and NDIS supports available, and equitable responses to similar

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<sup>26</sup> Paynter, J., Ferguson, S., Fordyce, K., Joosten, A., Paku, S., Stephens, M., Keen, D. (In Press) 'Utilisation of evidence-based practices by ASD early intervention service providers' Autism.

<sup>27</sup> Submissions by Dr Ros Harrington, rosamund.harrington@acu.edu.au

care needs, rather than a focus on maintaining plans within reference package budgets is advisable.

- VI. There may be a need for capacity funding of specialist organisations such as those working with people with spinal cord injury, ABI, mental health conditions, and early onset dementia to ensure these services are sustained as transition to full scheme maturity occurs, particularly to ensure the needs of people within rural and regional areas are met. Co-funding of mainstream services to maintain specialist follow-up services which have traditionally been health funded may also be required.

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