Author/s:
May, T;Forrester, M;Webber, M;Roberts, J;Spreckley, M;Scheinberg, A;Williams, K

Title:
Current status, opportunities, challenges and the paediatrician's role as the National Disability Insurance Scheme rolls out across Australia

Date:
2018-01-01

Citation:
May, T., Forrester, M., Webber, M., Roberts, J., Spreckley, M., Scheinberg, A. & Williams, K. (2018). Current status, opportunities, challenges and the paediatrician's role as the National Disability Insurance Scheme rolls out across Australia. Journal of Paediatrics and Child Health, 54 (1), pp.7-10. https://doi.org/10.1111/jpc.13641.

Current status, opportunities, challenges and the paediatrician's role as the National Disability Insurance Scheme rolls-out across Australia

May, T.[12], Forrester, M.[3,4,5] ,Webber, M.[6], Roberts, J.[7], Spreckley, M[8], Scheinberg, A.[2,3,8,9], & Williams,K[1,2,8].

1. Department of Paediatrics, University of Melbourne
2. Murdoch Childrens Research Institute
3. Victorian Paediatric Rehabilitation Service
4. University Hospital Geelong, Barwon Health
5. Medicine, Deakin University
6. Hunter New England NSW Government Health
7. Autism Centre of Excellence, School of Education and Professional Studies, Griffith University
8. Royal Children's Hospital Melbourne
9. Department of Paediatrics, Monash University

Acknowledgements

We wish to thank the William Collie Trust, University of Melbourne, and the Lorenzo and Pamela Galli Charitable Trust for their support of authors Dr May and Professor Williams.

Current status, opportunities, challenges and the paediatrician's role as the National Disability Insurance Scheme rolls-out across Australia

Abstract

The Australian National Disability Insurance Scheme (NDIS) is being rolled-out. Major system reform was welcomed by the disability community when announced. However, the changes that are necessary for this reform are bringing both opportunities and new challenges for families and professionals alike. At the individual professional level, paediatricians will continue to play a crucial advocacy role supporting families negotiating access to appropriate funded disability services for each eligible child. As a group paediatricians have much to offer, including experience of mechanisms that will foster cross-sectoral collaboration to support vulnerable children and an understanding of the evidence to guide efficient and effective best practice early intervention and disability therapy services. To have an impact as a group paediatric peak bodies must forge opportunities to provide expertise to the clinical governance of the evolving NDIS. Action at an individual and group level will be crucial in ensuring the NDIS realises its full potential for improved care and lifelong support for those living with a disability.

Key Words: National Disability Insurance Scheme, disability funding

The National Disability Insurance Agency (NDIA) is an independent statutory agency whose role is to implement the National Disability Insurance Scheme (NDIS). The NDIS aims to provide sustainable long term care and support for individuals with significant disabilities aged between 0 and 65 years. The scheme replaces fragmented state and territory disability funding with a national approach to disability support in Australia, drawing on an insurance model. The scheme aims to provide choice and control for individuals with disabilities. There are many challenges as well as opportunities for both individuals with disabilities and professionals with the deployment of the new scheme.

Current status

A staged roll-out was commenced in 2013 with trial sites to test prevalence estimates and level of need for support, as well as operating models to make refinements as needed. Around 30,000 participants accessed the NDIS at seven trial sites as part of its three year trial phase, which finished on 30 June 2016 [1, 2]. The disabilities funded include intellectual, physical, sensory and psychosocial disabilities, with intellectual disability now accounting for around 38% of participants and autism 28% since the roll-out commenced [3]. The median annual package cost is currently $AUD 26,011 (excluding participants with shared supported accommodation supports) [3]. As at 31 December 2016 there are over 5,000 registered providers and since 1 July 2013, $AUD 5.1 billion has been committed to 61,215 participants Australia wide for disability support [3]. Transition to the full scheme commenced on 1 July 2016 and during 2019/2020 the NDIS will be rolled out nationally and is expected to have around 460,000 participants [4].

The National Disability Insurance Agency (NDIA) currently reports overall experiences of 85% of participants to be “good” or “very good” [2, 5]. One recent study has explored parents’ perceptions of registering and receiving Early Childhood Early Intervention (ECEI) support for children under seven years of age with developmental delay through the NDIS [6]. This study reported most parents experienced no difficulties with the registration process (86%) or accessing funding (64%) and were satisfied with the NDIS and NDIA (62%) [6]. Taking account of the immense challenges of implementing the NDIS in Australia and the staged roll-out approach, these early findings indicate room for improvement, but are promising.

Opportunities and Challenges

There are a range of opportunities and challenges that will inevitably arise with transformational change. There has been inevitable disruption during the rollout. Services have been working across NDIS and 'old system' structures simultaneously, in some instances for long periods.

Information about goals and outcomes will be needed by the NDIA to justify the cost of interventions provided and this is an opportunity to increase accountability and transparency of services and their outcomes. A national scheme will also provide better opportunities to collect disability statistics in Australia which will in turn create a more detailed understanding of the types and locations of services that are needed and help plan future service provision nationally. Evaluation of the effectiveness of interventions and support services provided under the scheme will be a change that requires considerable adjustment by some service providers, but less by others. A shift in focus for federally funded ECEI to functional impairment, rather than requiring a particular diagnostic label, is one of the key opportunities to ensure all children who experience significant functional impairment will receive the support they need to improve their long term outcomes.

The NDIS also marks a significant change in the way private and public sector and non-government organisations receive funding. The NDIS is already promoting competition between service providers as participants are able to choose their services and change them if their needs are not being met. There has been an increase in the number of private service providers, for example, there are now over 55 private early intervention providers in Newcastle when there was only a few before the NDIS commenced. There are also opportunities to develop new technologies to aid those with disabilities as funding for technology that supports individuals with disabilities is available. While the new system gives people with disabilities long-awaited choice and control there are some downsides to market forces operating within a publicly funded framework [7]. For example, there have been reports of organisations with little experience in key areas of disability care winning tender processes. There may also be economic incentives to provide centre-based care, which minimises the cost of travel time for professionals, rather than care as currently provided in childcare and preschool settings. Market forces have also led to closure or acquisition by larger providers of small long-established services.

Services outlined in individual support plans have not always been available. In some instances because of an insufficient supply of suitably trained professionals, particularly in rural and remote areas [7, 8]. This will require a training response without an identified funding source.

The NDIA expects that 460,000 people will receive support under the scheme. However, with an estimated four million individuals in Australia living with a disability [9], this means that 9 out of 10 individuals with disabilities will not receive support through the NDIS [10]. As such, eligibility criteria are necessary for the system to work and will result in inevitable exclusions [10]. There are significant challenges in defining which one person in 10 will receive funding [10]. For example, the mental health model of “recovery” and the episodic nature of many mental health problems is contrary to the NDIS requirements for the funding of “permanent (or likely to be permanent)” disabilities [11]. The NDIA plans to fund individuals with chronic mental health problems and has recognised the variations in disability intensity that occur, for example by considering functioning over a period of time rather than a particular point in time [12]. The NDIA has established the Mental Health Sector Reference Group which includes consumers and peak mental health associations. This group is advising on the integration of psychosocial disability and mental health into the NDIS to ensure this group are not excluded [13].

The NDIA’s support for client autonomy and privacy, which is important and highly valued by many, is having an unintended consequence of creating barriers to best care. This is because the system is not designed to facilitate information sharing to enable cross-sectoral collaboration to support children whose parents have difficulty advocating for, or managing, their child's needs and capacities.

The insurance scheme requires the individual to submit their claim for disability support and prove their eligibility on a case by case basis and prove that their support will reduce their future dependence [10]. Individuals who are not literate in the process of choosing and self-advocating may be disadvantaged in accessing and using the NDIS where one of the key principles is self-determination, choice and control [14]. Given the social disadvantage, including poverty, low education and literacy levels of some groups and difficulties that could be faced by those from non-English speaking backgrounds, some argue that individually driven applications could result in additional disengagement and marginalisation [10]. Those who are able to advocate for their needs and understand the rules of the system and thus receive funding are like to occupy a position of relative advantage in the disability group [10]. Individuals with psychosocial or intellectual disabilities who are eligible to access the NDIS may not be able to communicate their needs and aspirations and thus may have difficulties developing future goals for a support plan [15]. In one trial site, registration was found to cause difficulties for parents who were poor, intellectually low functioning, drug and alcohol affected, affected by mental health issues, or those who had limited literacy or computer skills, or did not speak English, with refugees particularly vulnerable. As the NDIS is rolled-out to geographical regions where there are a high proportion of families with one or more of these characteristics, mechanisms to ensure they do not miss out on supports they and their children need will be required. This is especially pertinent as the children from families with these characteristics are known to be at higher risk of experiencing developmental vulnerability [16]. NDIA is currently considering complex case management support packages as one possible solution.

Even some well-informed parents who have taken on advocacy roles for their child in the past have described difficulties with the planning meeting, which is a main step on the pathway to receiving funding for necessary supports [17]. Parents have reported not fully understanding the range of difficulties their child is facing, not knowing how to set goals for management or make choices of which therapy is the priority, which therapists are the most experienced or relevant to their child's needs and which orthoses or mobility devices are the most appropriate. As such the role of the paediatrician, care co-ordinator, and other therapists is crucial in assisting families by providing information prior to the planning meeting that might assist decision making regarding their child's future therapy, care and equipment needs.

The NDIS does not fund education, health or housing services for people with a disability that are considered to be part of other service systems and tied to other funding arrangements. There may be difficulty defining the boundaries which separate the responsibilities of the health, education and housing systems from the NDIS. There is awareness and discussion about inevitable overlap which will hopefully create clarity of roles where possible and allow for conversations about the best pathways when role, and hence funding, delineation is not straightforward [5].

An insurance model that by design aims to minimise costs across the lifespan will also be interested in community resilience and capacity building and approaches to inclusion that are focused on abilities, rather than disabilities. Whether or not the funding provided for ECEI and packages, and the funding proposed for community and capacity building will facilitate this is yet to be demonstrated.

As the NDIA strives to maximise positive outcomes and minimise the negative impact of lifelong disability, and the personal and financial costs associated with this, they are seeking advice from experts and looking for best available evidence about all aspects of care that could impact their operation and services. Already paediatricians and other professionals have been engaged as consultants, have continued to act as advocates for children and young people, and have been invited to participate in advisory committees. More opportunities of this type are likely, especially during the development phase of the NDIS.

The role of paediatricians

There may be some changing clinical roles for paediatricians, with less diagnostic-based entry but more information about optimal care and support needed before parents can gain service access and participate in planning. Paediatricians can also inform NDIS policy to ensure timely and targeted interventions for infants and children as well as optimal allocation of limited resources. Paediatricians are well placed for this role because of their knowledge and expertise across neurodevelopment, injury and recovery, evidence-based interventions and best practice care and support. Already recommendations from paediatricians working in a trial-site have resulted in changes to NDIS service pathways. For example, at NDIS trial commencement only self-referral was allowed. In response to feedback from paediatricians, the professionals' referral form was developed. This has strengthened opportunities for paediatricians to work with the NDIA and families to provide care to all children who need disability services.

Some specific examples or areas where paediatricians could advise the NDIA include:

- ECEI provision before expected disability: Under current eligibility criteria for ECEI, infants at high risk of neurodevelopmental adversity but yet to manifest the expected functional delay or physical disability are not eligible for ECEI funding. For example, a neonate with extreme prematurity, hypoxic ischaemic encephalopathy or an in utero cerebrovascular accident does not fulfil current criteria for early intervention until the infant has a manifest delay / neurological abnormality. The potential benefits of early interventions in this group to maximise recovery and functional outcomes are encouraging [18]. Paediatricians and the NDIS could co-develop guidelines for monitoring and (where recommended) provision of targeted early intervention for these infants.
- Evidence based therapy: Paediatricians and allied health leaders could guide the NDIS in relation to evidence-based interventions, therapeutic best practice, and outcome measures. This type of input has the potential for improved outcomes for children and their families, as

well as cost savings that will assist long term sustainability of the NDIS to realise the full potential for lifelong support.

- System design to foster cross sectoral collaboration: Paediatricians can most effectively support children with disabilities and their families as part of a well-communicated and coordinated network. A system designed to support this is critical but there are persistent gaps that require further action to improve health and disability services interactions, as well as interactions with other services, including role clarity and improved communication that is sensitive to child and family privacy.

Some suggestions from paediatricians in trial-sites which would improve child and family care by ensuring important communication between health professionals and the NDIA are:

- A standard consent form for *two-way* information sharing to be offered to families at the time of intake (professional to NDIS and NDIS to referring professional).
- Agreed plans sent to the referrer and future clinical/therapy providers, without relying on the family as the information transferrer.
- Referrer notified upon receipt of a referral and informed about the likely waiting time until the intake and planning meetings.
- If a referred family decline or fail to attend a planned meeting the referrer be notified.
- All information provided by the paediatrician at the time of referral to NDIS be provided to therapy providers following allocation.

During the roll-out of the NDIS paediatricians will have ongoing roles to play working both with the NDIA and state and territory funded systems ensuring (1) children, young people and families receive the care they need, (2) optimal inter-sectoral communication, (3) important changes are advocated for and (4) paediatricians have a voice in decisions in which their expertise is needed. Although these roles are not new, this could be the right time for paediatricians to be more organised in the way they interact with each other and with the NDIS. A national system, perhaps overseen by an existing organisation like the Neurodevelopmental and Behavioural Paediatric Society of Australia or the Academy of Child and Adolescent Health, could be established to collate NDIS experiences and develop key areas of action. Such a system could provide more opportunities for impact, through a national paediatric voice, and more opportunities for learning in one sector to inform action in another.

Conclusion

The NDIS is reforming the disability sector in Australia providing a lifetime of support for individuals with permanent disabilities under a national system. With an underlying philosophy of making short-term investments to reduce long-term costs, the scheme aims to drive toward independence and maximise participation in society for individuals with disabilities. While there are many challenges for clinicians, families and providers with this transition and with some practical details still being developed "on the go", there are also numerous advantages over the old fragmented service delivery model. The opportunity for paediatricians to contribute, either individually or in a more organised way, their expertise to the iterative improvements that the NDIS is one that we cannot afford to miss.

References

1. Bonyhady B. The NDIS is a Platform for Innovation Australia: National Disability Insurance Scheme; 2015 [cited 2016 22-9-2016]. Available from: https://myplace.ndis.gov.au/ndisstorefront/news/ndis-platform-innovation.html.
2. NDIS trial – on time and on budget [press release]. NDIS2014.
3. National Disability Insurance Agency. COAG Disability Reform Council Quarterly Actuarial Report Version 1 December 2016. https://www.ndis.gov.au/medias/documents/hda/h8d/8800076922910/CDRC-Report-2016-17-Q2.pdf: National Disability Insurance Agency; 2016.
4. Australian Government. Disability Care and Support: Executive Summary. Canberra: Australian Government, 2011.
5. Bonyhady B. Every Child with a Disability Every Chance Australia: National Disability Insurance Scheme; 2016 [cited 2016 22-9-2016]. Available from: https://www.ndis.gov.au/news/bruce-bonyhady-every-child.html.
6. Ranasinghe T, Jeyaseelan D, White D, Russo R. Parents' experiences in registering with and accessing funding under the National Disability Insurance Scheme for early intervention services for children with developmental disabilities. Journal of Paediatrics and Child Health. 2017 In press.
7. Malbon E, Carey G, Dickinson H. Accountability in Public Service Quasi-markets: The Case of the Australian National Disability Insurance Scheme. Australian Journal of Public Administration. 2017.
8. National Disability Insurance Agency. Rural and Remote Strategy 2016-2019. Feb 2016 ed2016.
9. Australian Bureau of Statistics. Disability, ageing and carers, Australia: Summary of findings. In: Statistics. ABo, editor. Australia: Australian Bureau of Statistics; 2012.
10. Soldatic K, van Toorn G, Dowse L, Muir K. Intellectual disability and complex intersections: Marginalisation under the National Disability Insurance Scheme. Research and Practice in Intellectual and Developmental Disabilities. 2014;1(1):6-16.
11. Williams TM, Smith GP. Can the National Disability Insurance Scheme work for mental health? Australian and New Zealand Journal of Psychiatry. 2014;48(5):391-4.
12. NDIA Mental Health Section, inventorNDIS Mental Health Key Themes2015.
13. Bonyhady B. Tides of change: the NDIS and its journey to transform disability support. Newparadigm: the Australian Journal on Psychosocial Rehabilitation, Summer. 2014;2014:7-9.
14. National Disability Insurance Agency. Operational Guidelines - Early Intervention Requirements: National Disability Insurance Agency; 2014 [cited 2017 1 March 2017]. Available from: https://www.ndis.gov.au/operational-guideline/access/early-intervention-requirements.html.
15. O'Connor M. The National Disability Insurance Scheme and people with mild intellectual disability: Potential pitfalls for consideration. Research and Practice in Intellectual and Developmental Disabilities. 2014;1(1):17-23.
16. Chandra M, Jalaludin B, Woolfenden S, Descallar J, Nicholls L, Dissanayake C, et al. Screen time of infants in Sydney, Australia: a birth cohort study. BMJ Open. 2016;6(10).
17. May T, Roberts J, Webber M, Spreckley M, Scheinberg A, Forrester M, et al. The roll-out of the Australian National Disability Insurance Scheme: opportunities, challenges and the paediatrician's role. Journal of Paediatrics and Child Health. 2017 in press.
18. Basu AP. Early intervention after perinatal stroke: Opportunities and challenges. Developmental medicine and child neurology. 2014;56(6):516-21.