

**Submission
No 4**

**INQUIRY INTO IMPLEMENTATION OF THE NATIONAL
DISABILITY INSURANCE SCHEME AND THE PROVISION
OF DISABILITY SERVICES IN NEW SOUTH WALES**

Name: Ms Jodie Bailie

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26th June 2018

Email submission from

Dear Sir/Madam

I am writing to contribute to the NSW Parliamentary Submission on the implementation of the National Disability Insurance Scheme (NDIS). I attach an article, published in Sept 2017 in the Medical Journal of Australia Insight, that outlines my experiences of the NDIS as a health services researcher, evaluator and a mother of a daughter who participates in the NDIS. Within the article I outline a number of calls to action to ensure coordination between the health sector and the NDIS.

Bailie J. (2017) Coordinating the NDIS and the health care system. MJAInsight.
Available at: <https://www.doctorportal.com.au/mjainsight/2017/37/coordinating-the-ndis-and-the-health-system/>

I am happy to be contacted further on this issue.

Regards,

Jodie Bailie
Research Fellow (Evaluation)
University of Sydney

Attachment 1: Article published in MJAInsight, available at:

<https://www.doctorportal.com.au/mjainsight/2017/37/coordinating-the-ndis-and-the-health-system/>

I RECENTLY attended the [Primary Health Care Research and Information Service conference](#) in Brisbane, and was surprised that at Australia's premier forum on primary health care (PHC) there was not one presentation on the [National Disability Insurance Scheme](#) (NDIS) and the impact of its rollout on the health system.

Australia is experiencing an unprecedented, once-in-a-lifetime, national reform with the implementation of the NDIS, yet at this conference there was no reference to it at all. We heard about the [Health Care Homes](#) initiative, which is also undoubtedly a major reform (although not on the scale of the NDIS), but there was no critical analysis of the intersections between the PHC system, Health Care Homes and the NDIS.

I understand that the NDIS is not a health scheme, and that in fact it specifically excludes health conditions; yet there are clear intersections with the health system at many points, particularly with its provision of funding for the support, services and equipment that people with disability require to meet their functional needs. I wonder why, more generally, there is such a dearth of research on, and critical analysis of, the effects of the NDIS on the health system. After all, coordination between the NDIS and the health system is required at all levels if we are to see improved health outcomes and quality of life.

As a health services researcher, evaluator and a mother of a child with a disability, I would like to share some early personal experiences on this intersection (or possibly gaps) between the health system and the NDIS. In doing so, I will identify a number of areas for action that I believe the government needs to address, and a call to arms for those interested in systems thinking.

I recently attended my daughter's first NDIS planning meeting – a meeting that is held to identify her goals and support needs, with funding then allocated to help her achieve these goals. She is 16 years old and has Down syndrome and various health conditions, including intellectual disability, a cardiac condition, vision impairment, hearing impairment and alopecia. Her NDIS planner went to substantial effort in documenting which of these conditions are linked to her disability and which could be unrelated. It is on reflection and after more reading that I can see that what they were trying to ascertain was what is the responsibility of the health care system and what is the responsibility of the NDIS. In other words, they were checking which system had responsibility and which should bear the cost of different aspects of care. They were clearly alert to the potential for cost shifting.

Our GP, who currently manages my daughter's care, was not involved in the planning session, nor will be sent any documentation of the agreed plan. With GPs being left out of a major part of planning and care for people with disability, how does the NDIS model fit with primary health care in Australia? According to the Royal Australian College of General Practitioners, ["general practice provides person centred, continuing, comprehensive and](#)

[coordinated whole person health care to individuals and families in their communities](#)". This will no longer be the case for aspects of care that are the responsibility of the NDIS. GPs were previously seen as the central point of coordination of care for people with a disability, and now it seems that GPs will be coordinating care for people with a chronic illness or aged care only.

What happens for people with a disability and a chronic illness? Who coordinates their care and what is the role of GPs in this situation?

I want to make it clear that I am very supportive of the NDIS as a way to enable people with a disability to have choice and to pay for the services and supports that best suit them. I am calling for some critical analysis and evaluation to ensure we integrate the NDIS and the health system. [Neither the NDIS nor primary care can act in isolation](#) and there is a [need for integration](#). Rather than seeing my daughter's care as being person-centred and holistic, there is a risk that we are creating silos of care by separating out disability and health conditions. We need both the NDIS and primary care to come together, to work together, [to ensure key needs are managed in a coordinated way](#).

A call to action:

- There is a risk of people falling through the cracks because of potential cost shifting between the NDIS and the health system.
- The NDIS and the health system reside in different government departments (Social Services and Health respectively). There is a need to build rigorous system-level evaluations and to enhance communication channels between departments.
- Coordination of care between GPs and NDIS service providers is needed to ensure that information is shared to improve patient outcomes and to avoid fragmentation of care.
- The funding model needs to be evaluated to ensure that there is reasonable access for people who do not have NDIS funding or who rely on Medicare-funded visits (eg, people with a chronic disease). The NDIS pays a much higher rate to allied health providers than Medicare-rebated or privately paid services, so there will be the temptation to prioritise NDIS patients to the detriment of others, particularly given the shortage of allied health providers – especially in rural areas.
- Excessive demand on allied health services will be exacerbated with the additional need for their services by patients who will now have access to funding to pay them. There is a need to look at bolstering training of allied health professionals to meet the demands.

Jodie Bailie is a research fellow (evaluation) based at the University of Sydney's Centre for Rural Health, North Coast. She is the mother of three children – one of whom participates in the NDIS.

Ms Bailie would like to thank Helen Fisher, the director of [roundsquared](#), a social purpose organisation supporting people in the NDIS, for her review and comments on this article. Previously, Helen Fisher was the CEO of Southern NSW Primary Health Network. She is the mother of two daughters who are participants in the NDIS.