THE UNIVERSITY OF SYDNEY

Submission Productivity Commission

National Disability Insurance Scheme (NDIS) Costs

Section 3 – Scheme Boundaries

Submission

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Introduction

I have read through the Productivity Commission's National Disability Insurance Scheme (NDIS) Costs consultation document and thank you for the opportunity to provide feedback. I focus my submission in on the questions relating to the interface between the NDIS and mainstream services and mental health related services which arise from **Section 3 on scheme boundaries.**

Responses to individual questions

Question: Can the way the NDIS interacts with mainstream services be improved?

I recently completed a systematic, rapid review of the literature on the interaction between disability and mainstream health services which was commissioned by National Disability Services. That review found that **interactions between the sectors were hampered by the following factors:**

- Different professional 'silos' of working have developed which mean that different practices and forms of knowledge tend to dominate work in disability and health and other types of knowledge are not accepted as valid in comparison.
- Health and medical care tends to operate within an 'acute mindset' and is unfamiliar with the timelines, processes and interactions involved in long-term care.
- With increasing specialisation there has been a reduction where professionals work only within particular 'disease boundaries' even within healthcare, so specialists feel unprepared to assist those whose needs lay outside of their direct speciality.
- Because of demands on time services may be too rushed to take the time with people with complex needs and work out appropriate care plans through communicating across sectors.
- Health practitioners often feel that they lack skills in providing care to people with a disability and have reported feeling difficulty in answering questions posed by people with disability about their care.
- Physical barriers regularly limit access to services by people with disability including a lack of accessible transportation and inaccessibility of buildings, rooms or equipment. This will only be solved through the use of ILC funding where a service is motivated to access the funding. This is unlikely to care in mainstream services that are only irregularly accessed by people with a disability.
- Some services actively exclude people with particular needs, for example some health or disability services are not available to people who experience drug and alcohol addictions.
- Organisational barriers often result from poor communication, including:
  - Poor cross-service working because of a lack of understanding about who to make contact with.
  - Incorrect 'assumptions' about other sectors and organisations and what they do.
  - Competitive funding arrangements which have led to increases in organisational privacy concerns.

- While annual levels of GP contact amongst Australians with disability are generally high (94.9%) people with disability and their carers often report low satisfaction levels with health care generally. Key areas in which they report low satisfaction include high waiting times for service access and poor communication.

These factors stop consumer goals and individualised plans being developed or shared across systems. It also stops those with a disability from accessing physical health care. With the life expectancy of people with mental ill-health, for example, more than ten years less than the general population this poor intersection between the sectors needs to be addressed.

The funding arrangements for the NDIS do not help these problems because they do not provide incentives for collaborative working between sectors, relying instead on mediators to link up the system. The systems may be linked for them but the treatment or practices of the other sector still fall short of meeting their needs in an appropriate way.

Particular strategies identified in the literature review that could be funded for successful inter-sectoral working include:

- Funding of inter-agency forums on particular health or disability-focused issues and working groups which develop shared action projects.
- Active development of connections between key individuals. In the Hunter NDIS trial site connections with General Practitioners and Practice Nurses were actively made in order to engage these professionals (who are sometimes isolated in communities) in order to increase connections.
- The use of flexible funding pools to promote shared projects which build cross-sector capacity. This has been used effectively in this way in the Partners in Recovery mental health program.
- While a focus on cooperation and collaboration needs to be built into each role in the system there should be primary roles funded with a responsibility to make sure that this is happening.
- Co-production of the system with carers and consumers through the creation of ‘learning networks’ or ‘local coalitions’ involving consumers, carers, practitioners and administrators. Consumers and carers have a unique insight into the practical difficulties in cross-sectoral working.

The full literature review which this text is taken from, including relevant references, is available from the Centre of Applied Disability Research. **http://www.cadr.org.au/about-cadr/research-to-action-guides/working-collaboratively-at-the-interface-of-disability-and-health-services**
Citation: Smith-Merry, J. (2016) *Working collaboratively at the interface and health and disability services*. Research to Action Guide, Rapid Review. Centre for Applied Disability Research.

Questions:
How will the full rollout of the NDIS affect how mental health services are provided, both for those who qualify for support under the scheme and those who do not?
What, if anything, needs to be done to ensure the intersection between the NDIS and mental health services outside the scheme remains effective?

A lack of existing data:
These are important questions but data on the journey of mental health clients of NDIS remains scarce to non-existant, so they are difficult to answer. It is important that the NDIA release information for research and program monitoring so that the journeys of those with mental ill-health enrolled in the NDIS can be compared to those not receiving NDIS support, for example those receiving support through Partners in Recovery. This is an important comparator group because while many Partners in Recovery clients would have been eligible for NDIS, some

were not. It is therefore feasible to track them as a cohort to determine the impact of NDIS over existing care.

The same services are needed for people both with and without access to the NDIS: Because of the episodic nature of mental ill-health many of the same services will be needed for those who are eligible for NDIS and those who are not. An analysis that I have conducted of the flexible funding provided to individuals through Partners in Recovery in Western Sydney showed that most money was spent on crisis-related support or support dealing with the after effects of a crisis which may have led for example to unstable accommodation, a lack of material resources including beds, whitegoods and food. Funds were also used for psychological care and physical health care. Only some of this is available under NDIS funding which means that these clients who have now transitioned from Partners in Recovery to NDIS will need to find this support elsewhere. Specific data related to this research is available on request. The interactions between Partners in Recovery and the NDIS is a particularly important area to monitor. This is because people eligible for NDIS are being exited from Partners in Recovery but may find that important areas of need are no longer able to be met. Additional services to meet these needs unfunded through the NDIS may need to be developed to meet these gaps.

National Disability Services have reported that the Hunter NDIS trial site found that ineligibility of applicants to the NDIS was much higher for people with a mental health-related disability compared to other disabilities. Given this high level of ineligibility and the significant areas of need not funded through the NDIS it is imperative that existing supports be continued so that individuals are still able to access them.

Permanence does not sit well with a mental health system based on recovery: Mental health does not sit well with a criteria based on strict (life-time) permanence. There is a significant disjuncture between the values underpinning mental health support in NDIS and outside of the NDIS (for example under the National Mental Health Plan). The main underpinning value structuring mental health care and treatment is 'recovery'. Recovery is also a core value promoted by the mental health consumer movement. Recovery is directly contradicted by an inclusion criteria focused on permanence. It would be significantly problematic if mental health consumers felt that they could not embrace recovery for fear that they would lose their NDIS support and receive something much less, but still needed outside of the NDIS. Recovery needs to be reconsidered in the context of the NDIS to ensure that the values through which it operates are congruous with the values of recovery.

The funding structure makes it undesirable for services to provide support for people who may be deemed to be difficult: The current funding structure does not make it appealing to services to develop services meeting harder to reach mental health related clients which are by their nature more expensive to deliver. For example people who are deemed to be 'difficult' or 'unreliable' because they are seriously unwell, homeless or have a drug or alcohol addiction will involve much more effort on the part of services for the same service type to be offered. For example service delivery in this context can entail multiple attempts to make contact with clients. Recent research that I conducted into service delivery with people experiencing mental ill-health transitioning from jail found that those services which did not have statutory responsibility to provide services were more likely to abandon attempts to provide care for clients. There needs to be an incentive for developing services and engaging with these clients.

Question: What, if anything, can be done to ensure the ILC and LAC initiatives remain useful and effective bridging tools between services for people with disability?

The ILC will be an important tool in developing or enhancing services to meet the needs of people where services do not currently exist. This is particularly important in 'thin markets' and within rural and regional contexts. This is an issue that myself and another colleague from the

CDRP spoke about in a recent Croaky article on indigenous access to the NDIS (Gilroy and Smith-Merry, 2017).

Data needs to be developed which captures gaps:
Data should be created through standard NDIS record keeping and made available that attempts to understand current gaps, for example: what do people require on their NDIS plans that they cannot currently receive because there are no services operating? Our research on the implementation of Partners in Recovery in Western Sydney showed that one of the highest levels of need identified was for company and daily activities, yet a mapping exercise conducted by Professor Luis Salvador-Carulla (also from the Centre for Disability Research and Policy) showed that there are none of these services operating in Western Sydney (Hancock et al 2017; Fernandez et al, 2017). Service mapping against client need will assist with identifying gaps which will allow the ILC funding to be better targeted.

The comments above about the desirability of creating services for niche, difficult or 'unglamorous' needs (for example continence services) ring true for non-mental health related services too. Those services which are required to be delivered in remote areas or to clients with communication barriers (e.g. all materials need to be translated) will be more expensive to provide. There needs to be an incentive to meet the needs identified through service mapping and needs assessment which might be more difficult to produce or more expensive to develop to ensure that there is not an inequality in the operation of the NDIS. If these costs are passed on to clients then some NDIS participants will find that their NDIS budgets do not stretch as far simply because of where they live, what language they speak or the niche nature of their needs.

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.

References:

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