11 July 2017

Productivity Commission
Canberra ACT

Dear Sirs/Mesdames

NDIS Costs submission

I make a submission regarding the position paper published by the Productivity Commission on 14/6/17 regarding the National Disability Insurance Scheme costs (the Paper). I set out below my individual submission, with accompanying personal information to illustrate the issues. My experience does not encompass all issues discussed in the Paper so I have no opinion on many aspects of the Paper.

I applaud your work on the NDIS, which I hope will improve the quality of life for my son and many others who were inadequately supported under the state-based system of disability services. I agree with your Paper that there is "considerable unmet need in the disability support sector" and see this as an indicator of significant dysfunction in the state disability service systems. This is relevant in considering slowdown of the NDIS rollout and the extraordinary usage to be expected under the NDIS over the coming decade in order to try to address the backlog of unmet needs accumulated over decades under the significantly underfunded state-based disability systems.

Background

My 17-year-old son (J) requires constant high level care. I made a submission to your office 7 years ago regarding your inquiry that led to the introduction of the NDIS. In that submission I wrote "Each year my mental, physical and pecuniary resources are substantially diminished by the impossible task of caring for my disabled son. At some time in the coming decade all my resources will be depleted by this task, then I will have to renounce the care of my eldest son to the State". J's intensive, complex needs and behaviour also had significant effects on his father and sibling. I placed my eldest son into voluntary out of home care in NSW in October 2015. I remain actively involved in my son's affairs as his decision-maker and loving mother.

Since 2015 my son has lived in a house owned by the NSW Government which is treated as emergency accommodation by the NSW Department of Family & Community Services (NSW FACS), not as a group home. People living in group homes have clearer security of tenure and an organised system to roll their continuing accommodation into the NDIS. People living in non-group homes (like my son) do not.

J is well served by his home and I want him to continue living there. NSW FACS is taking steps currently to evict J from his home. NSW FACS has identified no alternative accommodation other than their suggestion in July 2016 that he should move back into my home, despite my clear statements since 2015 that J can no longer live in my home. On XX/XX/XX I was advised by letter from XXXXXX for NSW FACS that the consent to utilise J's home expires on 30 September 2017 and it is essential that J move prior to this date. J's housemate has also been informed by NSW FACS that he must move out. The reasons why NSW FACS have decided to evict J on this date have not been explained to me, but apparently NSW wants to empty this house and sell it on the open market. These facts are relevant regarding my submission on the service gaps and boundary issues that are causing problems due to lack of continuity of support from NSW.

We live in the eastern suburbs of Sydney so the NDIS started in our area from 1/7/17. J does not yet have a plan under the NDIS.

Scheme Supports

Regarding Information Request 4.1, I submit that the NDIS Act is not sufficiently clear regarding the meaning and application of the 'reasonable and necessary' test. Better, more detailed direction is required from the legislature.

Boundaries and Interfaces with the NDIS

I strongly agree with Draft Recommendations 5.2 and 5.3 in the Paper.

The states continue to have responsibility for child protection including in relation to children with disabilities. There are significant boundary issue between the NDIS and state child protection responsibilities. In the last six months it has been suggested by NDIA and NSW FACS staff to me and my acquaintances that the NDIS will not provide Supported Independent Living (SIL) nor Specialist Disability Accommodation (SDA) funding for children. This is a fundamental boundary issue that is causing significant consternation among affected families. Some providers say they have seen NDIS plans for children containing SIL and SDA. The NDIA should publish urgently a clear statement on these matters.

Surely it must be obvious to any informed person that it is reasonable and necessary for a very small percentage of children with severe disabilities to live away from the family home with high levels of attendant care. These children require very expensive care as children and into adulthood and a family cannot reasonably be expected to provide high levels of intensive care for many years. Planning for this cohort should have been a priority for administrators. The boundary of cost sharing between the NDIS and states in this area related to children should have been resolved by now and a public guideline published.

In my experience there are already problems emerging related to the interface between the NDIS and State disability services regarding the provision of accommodation for people with disabilities, particularly accommodation that is not labelled as a 'group home'.

In recent years NSW FACS appears to have been anticipating the start of the NDIS and setting up new group homes by preference in rented accommodation (not accommodation owned by NSW). NSW FACS decides which homes are considered group homes (not respite homes nor emergency homes) and seems to prefer to keep the number of group homes low in comparison to need.

NSW decided not to place my son on the Accommodation Support Register until after he turned 16 in late 2016. Due to NSW resisting placing people in group homes, particularly children, this interface issue affects a significant number of children with disabilities who have been living in 'blocked beds' in respite homes or in emergency accommodation like my son. The boundary issues between NDIS and child protection need clarification in written public policies.

NSW has not been sufficiently open with the public about its position on the continuity of support in respect of providing non-group home accommodation for people like J. Action by NSW toward my son has shown an unreasonable lack of willingness to provide continuity of service in this context.

I have applied for NDIS funding for SDA for J. I want to set up a new robust SDA home for J and two other young men with disabilities as soon as possible. However it must be expected that it will take many months (after J has a NDIS plan approved) to set up a new SDA home with appropriate approvals and modifications after reasonable transition planning. There is also the difficult issue of finding acceptable housemates to live with J, with which process NSW FACS has not been helpful.

It is essential that NSW continue to provide accommodation for J and others like him until we have been given a reasonable amount of time to find and set up new accommodation under the NDIS. My family provides an example of one of the service gaps opening up due to unreasonable haste by NSW in withdrawing disability accommodation services for a child before the NDIS has had time to fill the gap. I request that these issues be addressed as a practical example of boundary issues as discussed in Draft Recommendations 5.2 and 5.3 in the Paper.

Provider Readiness

I agree with Draft Finding 6.1 in the Paper.

In respect of Information Requests 6.1 and 6.2, I am concerned about the effects of thin markets and slow transition on the provision of supported accommodation for people with complex, high intensity needs or very challenging behaviours. Since 2015 when my son has been in out of home care, I have seen high staff turnover rates and difficulties in retaining organisations willing to act as the designated agency for J's home. I submit that the NDIA must set up a provider of last resort for these thin markets so there is supported accommodation for high needs cases spread throughout the major population centres in Australia.

There needs to be real incentive for providers to take action to address these thin markets. I think it unlikely that relying on mainstream providers or leveraging community organisations can meet the needs of these difficult market segments for supported accommodation.

SDA funding is a very good idea but it is not yet workable for new households. Putting a household together to contain multiple people with high support needs and challenging behaviours who wish to live in the same geographical location is very difficult, even in a big city. How does the NDIA expect these people with SDA funding and/or high levels of SIL funding in their NDIS plans to find each other and work out whether they are compatible? There is a very high economic risk in providing these services over the transition period when participants must find each other and the right home.

I am pleased by observations in the Paper that the NDIA is aware of some current problems and plans to have more active involvement with communities. The NDIA should focus significant attention on building communities among participants with high NDIS budgets, particularly those with high support needs or SDA funding. Local respite services which provide respite for people with high support needs may be a convenient starting place for the NDIA to help community building.

An additional, simple measure the NDIA should take to address transition and thin markets for high needs supported accommodation in larger population areas is to support people with disabilities (and their carers) in finding each other so they can set up new supported accommodation themselves. I suggest that the NDIA take urgent action to set up and/or advertise voluntary opt-in services for people wanting to communicate and consider compatibilities with other people in the same geographical area for setting up a small home. The NDIA and state disability services have the contact information for the target market (who have, or are likely to have, approved SDA funding and/or high levels of SIL). The NDIA and state disability services have a vital role to play in educating participants by informing them of services to help them find each other by, in essence, providing marketing information about family connection services.

I am aware that the federal government provided some set up funds for Supporting Independent Living Co-operative (SILC). SILC is a co-operative of families of people with disabilities in NSW and Victoria which has set up a website to provide a forum for carers of people with severe disabilities to try to connect with others who may wish to set up a new household. There must be other similar organisations and websites but they are new and not well known among the target audience of carers of people with severe disabilities who have approved SDA funding or high SIL. These organisations seem to be taking over part of the role provided by the NSW Accommodation Support Register. They need the support of the NDIA and state disability services to become known to potential users as soon as possible.

Many families are able and very motivated to set up new homes for their family member to share with others. It is in the interests of the NDIA to take extraordinary measures to facilitate this, as it is a quick and effective channel through which many new homes for people with disabilities can be set up over the transition period. Homes in which families are actively involved provide a better quality outcome for participants with lower risks of abuse. Assisting families to find each other will reduce the financial risks in setting up a new home. It will also significantly reduce NDIS SIL costs if people wanting to set up new share households for people with disability can find each other and share costs, particularly overnight carer costs.

There are also transition issues for children in emergency accommodation related to SDA homes and turning 18-years-old. Normally children in out of home care can only live with other children so SDA households may need to alter as each child turns 18. The NDIS and state disability services should look at setting guidelines to cover these boundary issues and allow compatible people in SDA homes to continue to live together despite some housemates being adults and some being children.

A greater supply of SDA homes over transition could be encouraged if the NDIA worked with state governments to obtain state supports for SDA homes, for example, exemption from land tax and simplified regulatory approval processes for SDA houses.

A greater supply of SDA homes over transition could be encouraged if the NDIA worked with appropriate participants who have found housemates to share with, by fast-tracking SDA funding for those participants.

Workforce Readiness

I agree with Draft Finding 7.1 in the Paper. I agree with Draft Recommendations 7.1 and 7.2 in the Paper. I have seen significant staff turnover at my son's home due to visa restrictions. Many workers from Ireland (on short-term/one year 457 visas I think) seem to work in disability services and are very welcome. I submit that the federal government should consider relaxing immigration rules to help cover the expected shortfall in trained and experienced workers in the disability sector.

I agree with Draft Recommendation 7.3 in the Paper on the general principle of relaxing NDIA guidelines on paying informal carers but I do not agree with the proposed conditions for these payments set out in the bullet points in 7.3.

In relation to Information Request 7.2 I have experience regarding demand for respite services. Despite my son living in out of home care since 2015, he still goes to respite at my request. The respite service provider has staff who had formed positive relationships with my son that I want to maintain. I am also pleased that the continuity of respite gives my son exposure to different carers for some community access apart from the carers at his home. I expect to continue to demand respite services under the NDIS. I would expect the SIL costs for respite services to be similar to SIL costs provided via the service provider at a participant's home.

Governance

I agree with Draft Recommendations 9.3 and 9.4 in the Paper.

In relation to Information Request 9.1, I request you recommend limiting as much as possible any slowdown in the rollout of NDIS. Many families have suffered severe hardship under inadequate state disability services and have been waiting patiently for the NDIS over the seven years since your inquiry began the NDIS process.

If slowdown must occur it should only be targeted to apply to people with low support needs. People with complex or higher support needs, or needing early intervention, would be at greatest risk from slowdown. I know from experience how desperate some families can feel under inadequate state disability services Even a delay of one year could precipitate a significant tipping point for some people. A delay in transition to the NDIS may cause a spike in families relinquishing the care of people with high support needs.

Slowdown should not be applied across the board nor to particular geographical areas.

Other Submissions

I have had the benefit of reading other public submissions to your inquiry on your website and wish to endorse submission PP219 written by the Autism Association of WA.

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Please respect my privacy and do not publicly identify me in any way in the course of your inquiry. You should add my submission to the public record of submissions after removing my identifying details.

Yours sincerely