



**Inquiry into the implementation, performance and
governance of the National Disability Insurance
Scheme in the ACT**

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1/22/2018

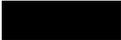




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Policy questions for the National Disability Insurance agency (NDIS) and the ACT government

The NDIS is undoubtedly a positive step for many people in Australia - for those with physical disabilities, for those who can speak for themselves, for those who need basic levels of care and most importantly - for those whose behaviour is NOT a leading issue. Those whose problems centre on behavioural issues are a whole new ball game that you do not seem to understand or factor into your policies but so many of your clients fit this category.

Here are some of the issues I and other parents of NDIS participants with high support complex needs in the ACT face and have not been adequately dealt with by either the Commonwealth or ACT governments since the transition to the NDIS. Both governments must rise to the challenge and resolve the policy implications of the following issues rather than seeing parents and NDIS participants with high support needs crash and burn. The euphemistically named informal supports (read carers) burn out and then the government will end up both funding and arranging or providing the full time care of high support complex needs clients.

On the CASPAR Facebook group I have seen very sad posts by parents usually mothers of NDIS clients with complex support needs and challenging behaviours and the issues they face when dealing with providers and the NDIS planning process. I also have had personal contact with other parents of teenagers and young adults with autism and difficult behaviours and heard the same issues over and over ad nauseum. The constant obstacles they face due to these adult children usually men, are aggression and other euphemistically called challenging behaviours. This apathy towards providing real support for these carers and their adult children worries me because there is no policy response to help these families. My son at almost 18 can also be aggressive and have behavioural outbursts and I do not want to have to continue caring without adequate support from both the NDIS and providers in the ACT able to provide the services he needs.

Many clients in the NDIS with aggression and challenging behaviours do not really fit the model of having choice and control. To be brutally honest many providers do not want to have to provide services to them because they are aggressive, hard to handle, cause endless problems, are an occupational health and safety issue for staff, and the list goes on.

Here then are some of the issues in Canberra that I have come across:

Respite

The NDIS seems to naively believe that informal supports in the form of aging parents will continue on and be able to cope. My own and other families who use Marymead to provide overnight respite had a saga of misery last year. The NDIS stupidly capped the overnight fees for respite so Marymead had the quandary as to whether or not they could continue to provide this service. Marymead as a provider has to pay their staff and many of these clients who use overnight respite fit into the category of complex needs. Such clients often need one-on-one support which the NDIS deemed as not to be part of their support funding. In our case as a couple without a regular break from our son's ongoing care we will not survive as a couple or be able to continue his care. My spouse and I

[REDACTED]

are both late middle age and have ongoing health issues. Other families also fit into the same boat as the two of us and need respite to continue on providing high need support to their children. Making difficulties for a provider willing to provide overnight respite for such families is stupid on the part of the NDIS and shows that some of the NDIS policy staff and actuaries have no idea of what families deal with in real life. In the Marymead case the NDIS contributed stupidly to the monkey on the back problems for families and hindered rather than helped us to continue on as our children's informal supports. None of us as parents needed to wage a bitter and protracted advocacy campaign so we could retain overnight respite. What must be understood is that most of us have enough as it is to manage and cope with.

This then leads me on to another aspect of respite which is not taken on board by the NDIS and let's face it the ACT government. By relying on private market operated providers you are lessening the supply of overnight and day respite to families. There are few options for respite for those NDIS participants who are over 18 as several providers have pulled out of respite provision. There is now only Marymead and the Disability Trust that I am aware of. This question has been raised by several posters on the CASPAR group. Typically these are single mothers of young adults with autism who provide ongoing support by themselves and have no one else to call on. Moreover the needs of carers on the death of a partner or long term illness or surgeries of their own never seem to crop up in the new NDIS reality. If there is no respite what do informal supports do when their own health needs must be factored in? In my own case without my spouse, should he die, I do not think I could keep caring alone

What is the NDIS doing to support the informal supports here in Canberra?

I am personally over the mantra put out by some groups that the NDIS is only about the participant. To me as a parent this is complete tripe. People like my son only survive in the community because we his parents and his sister are his support network. Without the family infrastructure he would not be in the community.

I cannot see that the NDIS consciously makes a real effort to support carers and other informal supports. Personally I know two mothers who must work, who have had issues getting adequate NDIS funding for their children to attend day programs and other activities so they can continue to work. This situation worsens once their children have left school and require care during the day. Their request for adequate funding have been met with a gatekeeper mentality by some of the NDIS planners who seem to consider it their duty to determine what money such families need to care for their children without adequate consultation and thought. These mums have gone onto seek reviews of their children's NDIS plans and may go onto the AAT to seek redress. Why make the lot of those who sacrifice much to look after their child and be economically self-sufficient more difficult by an agency that should be helping them.

Under the ACT government there was a program that provided a good deal for carers over 60 or 65 who continue do look after adult children with a disability. This older carer program provided increased respite funding for both overnight and day programs to occupy these young adults and to ensure that aging parents could continue on. Yet this need was discounted under the NDIS regime.

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The NDIS regularly asks older carers what plans do they have in place for their adult children. As a parent and an active advocate I have begun to plan for my sons needs when he has left school so he has a happy life and is occupied as fully as possible. However does the NDIS understand that many parents are just coping? Instead of asking what plans do older parents have for their adult children, the NDIS needs to ask what can we do to facilitate any plans you have for your adult children to get assisted accommodation, be employed by a social enterprise or whatever? Helping families to actualise such plans is more realistic than dumping the whole issue back onto informal supports.

Provider regulation, standards and penalties

The NDIS as the new disability agency do not seem to have set standards for providers of both housing and day programs to cater for high support complex needs clients. Why cannot the NDIS register and regulate providers as the Commonwealth government does with aged care providers?

Handing the care of people with complex needs and challenging behaviours over to anyone but properly trained staff is a recipe for disaster. While privately run homes with unskilled staff may work adequately in many cases, the people with the highest psychiatric and behavioural needs cannot and should not be handed over to people with minimal or no training and experience. Yet the NDIS has set no standards over these issues.

Those with severe intellectual disability and behavioural issues don't usually live in group homes or by themselves as a matter of independence. They are there because the physical and emotional strength and age of informal supports (parents) are on the downward slope. The management and real improvement of people with challenging behaviours is a tenuous thing unless they are supported by staff that understand the issues and have appropriate training in how to manage problems caused by challenging behaviours. To manage such people a provider needs a team of these professionals who can provide lot of input in regard to acquiring sensory materials and behaviour programs. Expert staff are needed to help develop plans for behavioural support to ensure the safety of these NDIS clients and staff who worked to support them.

A typical infolding scenario in the NDIS environment is a client with challenging issues is on the top level of funding for his day program with a ratio of one worker to support one client. However when things start to unravel because the client is expelled from his first day program because the staff could not or did not to want to deal with him. The second day program provider is also reluctant to take on the client, but finally agreed under certain trial conditions. Once the client breaches these conditions the program provider in all "good conscience" can get rid of him. Finally a third provider decides after many meetings, that they could not accommodate the client in their program so the client and his informal supports are left high and dry. What should be noted is how many of these providers are registered with the NDIS. However the NDIS will claim it does not function to provide "whole of life" care or to police the private providers who are supposed to occupy the market place. No that is the beleaguered informal supports job or a mythical provider who does not exist. However now that the State government disability agencies are out of the picture or in some cases going the buck should stop with the NDIS.



This then raises the question what penalties are in place to ensure that providers work with informal supports, engage adequate staffing level and work out behavioural management plans to support and engage with difficult clients. Providers need to be held to account for just dumping difficult clients. Two cases I know of are Carers ACT telling a mother her son did not quite fit or was right for the group they had or Daryl's Den expelling a young man with autism because he proved to be difficult on two occasions. In the case of Carers ACT the young man tends to be fairly easy compared with others that I know.

However always penalising providers is not the best first step. Sometimes the NDIS needs to sit down with the provider and the informal support and ask what level of funding is required to provide one on one supports to the participant so they can attend the program. Negotiation with providers should be the first step towards remediating a NDIS client participation in a program.

Relinquishment

Several people and children with autism have been relinquished in Canberra since the inception of the NDIS here in the ACT. Children under 19 who are abandoned are left to the ACT government because they are considered then as wards of the state. However this is not a realistic option as few foster parents want to take on adolescents with behavioural issues and few of the providers of foster services to teenagers understand the needs of those children. Leaving them in teen respite or other holding places for long periods of time is not a good outcome for them.

Worse is the situation of young adults and older adults with ASD who are relinquished by their parents or other informal supports. There is few respite places to provide temporary accommodation for them until permanent supported accommodation is secured for them. This matter must be resolved and responsibility allocated between the ACT government and the NDIS. Having a policy limbo is not a good or just situation for these people.

Options that may work are adult fosterage as is considered and has worked for some in Ireland and parts of Europe. However such foster families I suspect for adults with ASD are very few and far between. What must be done with good will is for the ACT government to manage the solution and the NDIS to step up to the plate and provide adequate funding. All of this work hand in hand with helping families look into supported accommodation for their family members before it comes to an impossible situation and making this possible with the development of good supported accommodation providers and an encouraging space for families to think through their long term options. Having a supply of respite options means that families often continue providing care instead of just opting out because their needs for a break are factored in. However their long term plans for the person they care for must be encouraged and facilitated to happen.

Provider of last resort

Waiting lists for group homes and other supported accommodation places can be long and no not for profit or commercial NGO will be running to the front of the queue with their hand raised, yelling "pick me", to take on those with aggression or other challenging behaviours. So what actual choices will this leave difficult people other than TAKE IT OR LEAVE IT if they are lucky or just stay at



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home with your informal supports until they die. If a client is refused a group home place or other supported accommodation choice because of aggressive behaviour – where does he go? Who is the provider of last resort in this plan? In the changes due to the NDIS, providers still cherry pick to avoid clients with behavioural problems and so that leaves informal supports wondering who are the providers of last resort and how will they be funded to support the hardest to manage cases or if they will exist. Yet a large proportion of NDIS clients at level 3 fit this category.

When the NDIS covers all of Australia and have let all the states off the hook, it will be the country's last disability agency that will be stuck having to fund and probably organise support for these difficult clients.

Policy responses

So as part of this reality what policy responses has the NDIS and for that matter the ACT government come up with in answer to:

1. What is the NDIS and for that matter the ACT government doing to encourage more respite services?
2. What is the NDIS doing to monitor and regulate providers?
3. What is the NDIS doing to penalise providers who dump clients with challenging behaviours and complex needs?
4. What is the NDIS doing to develop the market place for providers who specialise clients with challenging behaviours to:
 - develop behavioural management programs
 - supported accommodation services
 - day programs or other forms of community access that work etc so and so on.
5. What is the NDIS doing about providers of last resort?
6. What policy responses has the NDIS and the ACT government come up with to prevent relinquishment and if needs be deal with it to ensure good outcomes for those who have been relinquished by their families?

The NDIS has this policy wasteland for those with behavioural issues from the state governments so it is really up to the NDIS to sort out with client advocacy groups and informal supports how to respond and to provide or nurture evidence based answers not just fund and hope for the best

Which government agency will there be, to support and deal with issues relating to people with complex disabilities and behavioural challenges but the NDIS and to some extent the ACT government?