Comments in response to the overview and recommendations for Disability Care and Support – Productivity Commission Draft Report.

Brooke Rudd

To be honest I found it rather difficult to gauge from the report how the NDIS would impact our family. I have a 4 year old child with severe autistic disorder and it was not clear to me how the services we receive and seek (two different things) would change under the NDIS.

That said, I wanted to express to the commission what I am after in terms of support for my child and our family.

Firstly, I am concerned about the wording of recommendation 4.5. My son accesses Applied Behavioural Analysis (ABA). This therapy has a strong body of evidence to support its efficacy (Prior and Roberts, 2006) ABA goes where the child goes. It goes to kinder, to playgroup, to swimming lessons, to the beach, the toilet and to bed. It is not appropriate to have a disjointed intervention whereby a child is treated by one group of professionals for after school therapy and another separate service at school. My son is in kindergarten this year. It was not simple to set up, but the 'Additional Assistant' he has at the kindergarten also works with him twice per week at home and in community settings. The AA is very well trained (well beyond the official requirements of the position) and has worked with my son for 2 years. This is how it should be. The kindergarten has listened to us, the family, and had regard to the strong body of evidence that supports ABA and they have been flexible to enable us to set this up. If we were not able to have this overlap we would need to have countless 'update meetings' and there would be much less efficiency. I would also be one very stressed mother as I know now, that he can go to kinder with his therapy being continued. The current teacher knows very little about Autism and nothing about behavioural techniques.

I do not support the idea that early intervention stops when a child turns 6 or begins school. Indeed many children are not diagnosed with Autism until they begin school. I understand the Victorian State Governement also shares my view and is extending its Early Childhood Intervention Service to age 8 – when a child is well within primary school. The approach that the family chooses to take with their child (assuming it is evidenced based) should be integrated with the child's education, be that at playgroup, childcare, kindergarten or school.

My child is a whole person. All in his life live by a behavioural approach to living with him, educating him, encouraging him to speak. This will be important to maintain for at least another few more years – well into primary school.

Box 2 (page 21) does not list "specialist education". Well, it's the education of both communication and academics that will improve my child's level of independence in later years. I don't really need "care" for my child, I need education, instruction and a supported environment for him to practice the skills he learns in his therapy. I strongly disagree with paragraph 3 on page 22. The evidence for this is simple. Schools commonly employ teacher aides for additional support in classrooms. But a TA will earn around $18-20/hr. Teachers themselves in their training receive very little instruction on teaching children with autism or other additional needs. Many families (including myself) are willing to pay for, or contribute to the cost of employing an ABA shadow in the classroom however

state school policy forbids this. I would like to ask the Commission to please be informed by Nicole Rodgerson at Autism Awareness regarding the importance of continuing ABA early intervention into mainstream schools. Phone (02) 9904 8130.

Other comments:

Recommendation 3.1: to provide individually tailored, tax payer funded support.

The only query I have with this is that would families and individuals have the option of adding private funds into the mix. For example, if a therapist a family was happy with could only be employed by an agency at a lower rate of pay, could the family top up the person's wages? We have been in this position where the official funded role required very few skills or experience and a pay rate of $16/hr, but we wanted a person who could add greater value.

Other situations could occur where a person is assessed as requiring X hours of physio or speech therapy but the client wishes to access more – will they be allowed to do so at their own cost?

This relates to Recommendation 4.1 – what happens when there is a difference of opinion. I would hope that by accepting the assistance of the NDIS a person is not limiting themselves to the decisions of the structure and is allowed to self fund without having to go to a separate provider.

Recommendation 4.4 – be careful with this one. Consider what is a therapy, and what is an extra curricula activity. I would hope that swimming lessons for kids with disabilities would be covered by NDIS. Not because it is a therapy (though many would disagree with me), but because it is an essential life skill that will be very difficult for us to teach without either specialist support or greater manpower (1:1 classes perhaps).

Recommendation 5.6 – natural supports

Families need to be protected from over-use. I find that because I am constantly seeking babysitting (or paying for childcare) for my daughter so I can get my son to appointments I am reluctant to then ask again if I simply want a break for myself. There are also issues with the care being for the person with a disability, well, we are 1 family. I don't want to use a respite service for my son but send my daughter elsewhere. Aside from logistics, I do not want to teach my children that they are different from each other, I do not want to separate them.

One last comment – I have heard families complain about restrictions is access time limited support. An example being assistance needed for 1hr to assist in transporting a child to school. Another example would be a short behavioural intervention session. I can envisage next year (the beginning of school) for our family that I may be after the services of someone to assist in getting my children ready for school (remembering that behaviour and life skills are the big issue in our family). Would workplace rules limit our ability to employ a suitable person (possibly a uni student) for only 1 hour? Any assistance provided need to HELP and that's the main thing with all this service provision. If it's too hard we give up.

Thankyou for taking my comments.