

Submission to the Inquiry into the Implementation, Performance and Governance of the National Disability Insurance Scheme in the ACT

I am a retired early childhood teacher who first starting teaching in the ACT in 1969. Apart from an 8 year break in service in the 1970s and early 1980s I taught continuously until 2003 when I resigned to establish my own Autism Consultancy. I closed this consultancy when the NDIS was first implemented in the ACT as I did not want to be involved, however tenuously, with another government agency. Apart from my first two years of my teaching career I have worked for the ACT government with children with disabilities from 18 months of age to the end of primary school. Although now retired, I volunteer at the ACT Playgroups Association's My Time and PlayConnect groups. I am also a member of the Autism Centre Advisory Group at Marymead.

The unique factors relating to the provision of disability services affected by the implementation of the NDIS in the ACT:

When the NDIS was first introduced into the ACT in 2014 all the Early Educational Intervention Programs run by the ACT Directorate of Education were terminated at the end of that calendar year and the money which funded these programs (teachers, teachers' assistants, psychologists/counsellors, running costs for the building etc.) was transferred to the NDIS. The abolition of these programs resulted in an outcry from the education disability sector as though similar programs of Early Education Intervention were not running in the states (they did however have 3 year old preschool programs unlike the ACT), these Educational Services for young children with disabilities they were exceedingly valuable in:

Providing these very young children with an educational setting where their potential could be developed and therapy programs be implemented in a user friendly environment. The children had the opportunity to experience structured, educational, developmentally appropriate programs where their individual needs were addressed and their therapy recommendations incorporated into the program. In addition parents were supported and able to form their own supportive self-help groups. The Early Intervention Playgroup also offered regular talks for parents on various aspects of their children's development and a social worker was available for crisis situations.

The programs that were running when the NDIS was implemented included:

- Early Intervention Playgroups for 2 to 3 year olds (originally when this group was started in the late 1960s children were enrolled from 18 months of age but as demand grew entry age became 18 months).
- 3 year old Early Intervention Preschool at Cranleigh and Malkara Schools.
- Early Intervention Units (EIUs). Children with a variety of disabilities or developmental delays aged from 3 to 5 years attended Preschool here. Maximum size of group was twelve children. Some children attended for one year, others for two.
- Autism Intervention Units (AIUs) for children with an ASD diagnosis from 3 to 5 years of age. These groups had a high staff ratio, 2 staff to 4 children.
- Specialised home and school visiting teachers supported children with Hearing and/or Vision Impairment from diagnosis (some started as babies) to the end of the child's schooling.

The ACT Government's commitment to providing tailored Early **Educational Intervention** is highlighted by the fact that early access was provided for young children with additional needs as far back as the 1960s. When I first taught at Chifley Preschool in 1969 each preschool had two *Special Places* for these children. These places were over and above the normal enrolment of 70 four year olds per teacher spread across 3 groups.

Special Places were replaced in the late 1970s/early 1980s by Assessment Preschools. These programs enrolled 10 mainstream four year olds and up to five 3 and 4 year olds with disabilities and/or special needs. Then in turn Assessment Preschools were replaced by Early Intervention Units.

I do not know for certain when the first Autism Intervention Unit opened but it was fully functioning in 1982 when I returned to the ACT.

As Canberra grew and the demand for places grew the Directorate of Education opened additional EIUs and AIUs.

These excellent early educational programs were all abolished with the implementation of the NDIS. Now mainstream preschools and schools, as well as some therapy services, are reaping the consequences.

These consequences include:

- Minimal support available for many, many children with disabilities who are attending a mainstream preschool; some start with no support at all.
- The children's lack of readiness and availability for learning in a group, however small the group, (poor sitting skills, poor listening skills, inadequate social skills, etc.).
- Some children with significant problems (mainly speech, gross motor, fine motor and emotional problems) not being identified until they arrive at school.
- Major disruptions in preschool and kindergarten classrooms as not all children are receiving adequate, if any, support.
- Behaviours becoming entrenched as some parents are not getting the support they need to assist their child before the child starts school. Some of these behaviours when entrenched become very costly to the community later on.
- Isolated parents as Early Educational Intervention groups were an excellent opportunity for parents to form lasting friendships and support networks. In current groups parents are focussed on therapists rather than other parents.
- Some parents don't actually access their child's package as they don't understand how to and/or are too busy. Indicative of the family not understanding the process.

Although some NDIS providers run small groups, they are fewer in number and offer fewer sessions per week than the Educational Early Intervention groups listed above. In addition the focus is on therapy rather than education and preparation for school.

Parents who utilized these Early Educational Intervention Programs for their first child but were not able to do so for their second, state that the lack of these programs have left the subsequent child inadequately prepared for mainstream preschool. In fact a parent has just told me that she has withdrawn her child from preschool as he is unable to cope in a large group of mainstream 4 years old children. Her child will spend another year at home having therapy and attend preschool in 2019. She is fortunate that her child's birthday is in March so the legal requirement to be at school at 6 years of age is not going to be a problem for her. I fail to see how the Directorate of Education can expect very young children with disabilities to benefit from and learn in a preschool program with their age peers where additional support is erratic and minimal at best - by 4 years of age the gap between many children with disabilities and their mainstream peers can be very wide indeed.

In addition parents who benefitted from the Early Educational Programs report that "watching the teacher or therapist working with my child was one of the most powerful things," "I could stand back from my child and observe how the teacher engaged my child." "Seeing it done is so much more effective than just being told what to do."

I would like to know where the money previously used to run the Early Educational Intervention Programs has gone. When the NDIS was being piloted we were told that this money would go to the NDIS

BUT as the NDIS does not spend money on education and many, many children are having to attend preschool with minimal support (most of the support is funded through the school of which the preschool is part, not the NDIS. It does not seem fair that money originally for education for the under school aged child is being spent elsewhere.

Schools are also experiencing difficulty working with the NDIS. Again major concerns focus around poor communication from NDIS, the complexity of the NDIS forms, the fact that many parents haven't really understood the process (what their child has been funded for and how it will be delivered), and the additional load of having to accommodate NDIS provided therapists in the school as many parents decide that they want their children to receive therapy at school.

The administrative staff at the schools' front offices have to ensure that each therapist visiting the school has current registration with Working with Vulnerable Persons as well as the appropriate level of insurance. As many parents want therapy delivered at school a member of the school staff has to draw up a timetable to ensure that there is a suitable physical space for each child to be seen. In some schools therapy time is restricted to recess and lunchtimes as space is extremely limited (many Canberra primary schools are fully enrolled). In some specialist schools a large number of therapists may wish to visit the school at the same time – this means that a school staff member has to arrange visits so that classrooms are not overloaded with adults thus becoming utterly chaotic. Then in many schools the Deputy Principal will meet with the provider before he/she starts working in the school. I acknowledge that therapists from Therapy ACT used to go into schools in the past but the frequency of visits and the numbers of therapist was much smaller than the numbers schools are currently expected to cope with. All this creates an additional workload not related to the core business of schools, education, for already very busy staff. Finally, children cannot be constantly taken out of the classroom otherwise their education, the reason for going to school, will be compromised.

Comments from parents attending ACT Playgroups Association's groups

- *Lengthy waiting times* for services are extremely stressful for families. The waiting list to see a Government Paediatrician is currently about twelve months and then there is a further waiting time for a government provided Autism Spectrum Disorder diagnosis and finally another wait (currently 12 months) before the NDIS provides funding to the family. Throughout this time parents are highly anxious because they know that Early Intervention is critical, they don't know what to do to help their child and time is passing. One parent told me that she had waited months to see a paediatrician and then had to wait an additional 2.5 months for the doctor's report before she could submit her application to the NDIS. This hardly builds parental confidence in this flawed system.
- The vast majority of families comment on the enormous stress they feel when dealing with the NDIS. They complain about *lack of transparency* in the system, *extremely poor communication* with the NDIS and changes in the NDIS' rules for accessing funding. The complex paperwork is another cause of anxiety and stress - the fact that they can no longer see a draft before the plan is sent to the delegate for approval (this used to happen in the ACT and still occurs in NSW), difficulties understanding the plan when it has been finally approved and that each year the money allocated to their child reduces, often significantly, even though the child's needs are still there.

Specific comments from parents:

- a. A number of parents have told me that the child's paperwork had been 'lost', in one case this happened three times.

- b. "After a wait of twelve months I only got in by writing to the Federal Minister. I was contacted by NDIS within twenty four hours and had the funding approved within two weeks. I had spoken to the Canberra Times as well but the story is being kept in limbo."
- c. "Communication with the NDIS leaves a lot to be desired. It is almost impossible to contact people." "You can never get to talk to the same person twice."
- d. "The stress they have caused - I am literally sick for weeks before a review meeting, having to think about all the therapy I want to ask for. Then not being sure whether I am going to get it. Thank God I did as I don't know whether I am going to have the energy to go through the review process again."
- e. "The processes are wrong. They make it hard and painful for families to deal with them." Forms are difficult to understand with no easy summary.
- f. "You need to know the NDIS terminology; e.g. swimming lessons are not funded even though the children will need years of individual lessons, but if the swim school will call it hydrotherapy funding is available."
- g. "The planners don't listen. I was given enough for my child to have speech therapy but no money for occupational therapy and psychology which he also needs. I was given \$1000 for a device which I didn't ask for, nor does he need it. I asked to use this money for therapy but was told that I couldn't."
- h. The planners don't follow recommendations from the child's therapists, even though the NDIS requests these reports (which are expensive for the parent to get). "How can a planner know better than a therapist who has actually worked with my child?" "Sometimes the planners haven't even seen the child!"
- i. "Once the funding has been established my child has made effective progress. I am grateful to the NDIS as I wouldn't be able to afford what he needs otherwise."
- j. "A lot of the questions in the generic questionnaires asked at the end of the appointment are stupid and inappropriate. I was asked if my 4 year old could cook his own dinner!" This does not build parent confidence in the system.
- k. Inaccurate information is given to families. A current family received a letter stating that the NDIS would contact the mother within 28 days. It is now five months later.
- l. "We have not heard whether the NDIS will accept her and we have been waiting for 6 months."
- m. I was told by an NDIS representative over the phone that complaining to the Minister would "buy delay for yourself." A number of parents have recounted to me this type of bullying and intimidation by the NDIS staff.
- n. "I have to access more than one service for therapy, as no agency has space to take my child for all three therapies." This leads to an extremely uncoordinated approach for the child and family. Either money has to be spent to arrange coordination meetings, rather than using it for therapy, or the parent has to act as the child's case manager.
- o. "We have spent all our savings getting her private speech pathology while we wait. She is still just as delayed and we are still waiting."
- p. Some parents are feeling desperate as some speech pathologists still say to parents "Bring him back when he can sit." "Keep her busy throughout the day so she will sit when we come at 4 o'clock." Parents are frantic as no one teaches the child how to sit and in the meantime the child is not receiving therapy.
- q. The rules keep changing. Currently the NDIS no longer funds a support worker to take children under 10 years of age out in the community. Parents have been told that this is the family's job as all other families do this. However what the NDIS fails to realise is that a child with a disability is extremely time consuming as well as being physically and mentally exhausting and that sometimes the parents would just like a break so that they can spend quality time with their other children. Prior to the NDIS a few hours of respite time was available to parents via FaBRIC which later became DUO. Where has the government funding that supported this respite gone?

- r. Removing funding for coordination of services for children under 10 years is another NDIS change that has recently been introduced. The comments in point q apply here as well.
- s. *"The person filling out my child's form couldn't even spell autism!"* As you can imagine this was hardly a good start for this parent's relationship with the NDIS as she came away wondering whether they knew what they were doing.

I accept that not all parents experience difficulties with the NDIS and that once the initial plan is written, reviews, although very stressful, are somewhat easier. *However, that any family trying to come to terms with being told that there is something seriously wrong with their child's development should have to struggle through the maze that is the NDIS is totally unacceptable.* Things should be streamlined and funding provided MUCH MORE QUICKLY! The future of these children and their families is at stake. I do not accept the excuse "We didn't expect to get so many clients in the ACT" any longer. It is almost 18 months ago since the original capacity figure was reached and as the NDIS has been running in the ACT for almost 4 years things should be streamlined by now!

I am extremely frustrated about the services being offered to children under school age. In May 2014 just before the NDIS trial started in the ACT the Minister for Education, Joy Burch, stated at public meeting in Holder that no child would be disadvantaged by the introduction of the NDIS.

THIS IS NOT SO -- CHILDREN ARE BEING DISADVANTAGED EVERY DAY!

I have also observed quite marked discrepancies in the funding children under school age receive. Families who are able to advocate strongly for their child seem to get more funding than families whose first language is not English and who may have cultural reasons for not being assertive. A migrant family I met with a 20 month old boy who had cerebral palsy affecting his whole body was given funding for therapy once a week (week 1 physiotherapy, week 2 speech pathology, week 3 occupational therapy) whereas a 4 year old child from an Anglo-Saxon family was receiving two sessions of speech pathology a week plus other therapies. It hardly seems fair!

In summary I feel that the NDIS has major problems with transparency, communication and waiting times. In addition it adopts a bullying and intimidating attitude with some families. At this point services for young children are undoubtedly a lot worse under the NDIS than they were before its introduction.

I would welcome the opportunity to come and speak to the members of the Inquiry about my concerns.

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