



**AUTISM
ASPERGER ACT**

Response from Autism Asperger ACT to:

*“Disability, Diversity and Tides that Lift All Boats:
Review of Special Education in the ACT”
by Professor Shaddock.*

Autism Asperger ACT Inc., a not-for-profit community self-help organisation run by a committee of parents and other interested people, works to improve the lives of children and adults with an Autism Spectrum Disorder (ASD).

Autism Asperger ACT's activities are focused on exchanging information, developing support networks and assisting the education and general community to learn how to help people with an ASD.

Autism Asperger ACT represents families who have students enrolled in all educational systems - Government, Catholic and Independent. Currently the diagnosis rate of ASD, among students between 8 and 12 years of age, is 1 in 100 which equates to 1% of the school population being somewhere on the autism spectrum. It is the commonest disability in the ACT school system.

Parents from Government, Catholic and Independent systems have all expressed concern to Autism Asperger ACT that many of the recommendations in Professor Shaddock's review have been raised with the ACT Government on previous occasions but change has not occurred. We trust that Professor Shaddock's recommendations will be discussed and speedily implemented.

We know that there are some excellent ASD friendly settings to be found within schools but many specific settings do not cater adequately for their students.

Vision and Scope for ACT Public Schools

Autism Asperger ACT agrees with Professor Shaddock that ACT DET should have a formal business plan. We trust that the development of such a plan will enable DET to have more authority within individual schools ensuring that the best interests of students with an ASD are considered at all times. At present, with school-based management as the model, DET can only make suggestions and not insist on

changes. In addition it is much harder to scrutinise where and how funds are being spent which impedes the process of accountability.

We are also in agreement with Professor Shaddock's suggestion that the term “*special*” be no longer used when referring to children with a disability.

Support for teachers and capacity building at classroom level

Autism Asperger ACT acknowledges that there is a huge variability in teacher knowledge and ability to work with students with ASD throughout all levels of schooling. Unfortunately many teachers are unskilled and view having a child with a disability as a burden rather than as an opportunity. The need to provide teachers with the skills to teach children with ASD is imperative and should not be left to the current ad hoc process. Although DET provides sponsorship for teachers to do additional study on ASD at the University of Canberra, not all teachers who teach a specific class for children with ASD have undertaken this or any other training. The chance of a mainstream teacher being “au fait” with the latest approaches to teaching children with autism is so unlikely as to almost be non-existent. Yet teachers are expected to provide a quality, evidence based education for some of the school system’s most challenging children who they do not understand and have no idea how to teach. The Federal Government, as part of the Positive Partnerships Initiative, has invested millions of dollars into providing teachers and parents with an online learning module which is free: www.autismtraining.com.au, as well as running local workshops. ACT DET has been involved in promoting the professional component of this to its staff but very few schools appear to be utilising the resources or training provided. Executive teachers in all schools should be factoring time for their teachers, particularly those with no experience of having taught a child with ASD. LSA staff with no training should visit this site and at least have some basic understanding of ASD issues. No wonder parents are frequently at odds with schools about appropriate disciplinary action for their children. The fact that many of these children do not look like they have a disability (children with ASD show no external sign of their disability like a child with Down Syndrome) does not mean that their needs should be overlooked.

We are aware that DET provides short in-services throughout the school year. However, it is often impractical for many staff to attend as they are unable to be released from school. They also may have other educational priorities that require additional study time.

Some schools do send teaching staff to in-services but in order to ensure a policy and attitude change throughout the school it is critical that principals and other school leaders also attend professional learning sessions specifically about ASD and commit to implementing what they have learnt.

Autism Asperger ACT recommends that education about and strategies for teaching students with Autism Spectrum Disorders be a system priority for all three education systems in the ACT.

The techniques recommended for children with ASD (talking in smaller chunks, explicit instructions, presenting work visually, having a visual timetable etc) do not harm the other children in the class. In fact they actively assist their learning, a fact that some teachers have found out to their surprise and delight!

Special Schools, Units and Centres

Autism Asperger ACT fully supports the parents' right to a range of educational options for their child with an ASD or any other disability. For some a segregated session offers the best choice while for others a fully integrated environment is the appropriate option. Other students move from one setting to another as their needs change during the thirteen years of education at school.

We are however concerned about the range of teaching approaches in the various Learning Support Units (Autism) in the DET. Although we appreciate that teachers need to tailor their approaches to meet the needs of the specific children in their class, some units use visuals (a recommended strategy) while others have actively removed them from the classroom believing that the child needs to learn to listen - (for a child who learns visually and may have auditory sensory issues!). This is an example of where a teacher's personal opinion is allowed to overrule evidence based research.

Preschool parents are also concerned that when they are looking for an appropriate setting for their child for entry into Kindergarten, they may be shown unit X which they like by the school counsellor, but the child is subsequently placed (through the central placement panel) in Unit Y where the programme is not only totally different but possibly totally unsuitable as well!

Autism Asperger ACT recommends that all autism specific Learning Support Units employ evidence-based approaches at all times and follow a similar curriculum.

Multidisciplinary Services

There is an urgent need for a reorganisation of therapy services in the ACT and we agree with Professor Shaddock that 'decisive and immediate action' needs to be taken.

Teachers are not trained as therapists - they need constant guidance and assistance in this area as the children in their care develop and change. Educational outcomes will improve when teachers are helped to understand their pupils better and also given the time to do what they are trained for, i.e. to teach.

Surely children with disabilities are entitled to have their basic needs met. Most, if not all, children with disabilities need assistance with communication and for many fine and gross skills pose problems as do behaviour, etc. To assist these children reach their potential, adequate services should be provided by the ACT government as a right. Sadly this is not the case at present - many parents have abandoned Therapy ACT as the waiting lists are so long and then, when children are seen, appointments are severely limited and staff turn-over is high resulting in an endless succession of 'first' appointments.

Schools do not seem to utilise the private resources that many parents are using. Strategies need to be put in place in schools to ensure that private therapists are welcome to visit the school, attend meetings etc. and actively engage with staff.

All special settings (special schools, units and centres) should have access to speech pathologists, occupational therapists and psychologists at all times. In special schools several professionals from each discipline need to be permanently based at the school in order to provide an appropriate level of service to the children and their teachers. Units and centres may be able to share their personnel across a couple of schools.

Autism Asperger ACT recommends that therapists be based in schools immediately.

Resources and resource allocation

Resources and their allocation continue to be a contentious issue between parents and schools. The Student Centred Appraisal of Need (SCAN) is not the transparent system DET claims it to be. Parents frequently state that they have to fight for resources and are concerned that the resources that are allocated for their child from the SCAN process are not necessarily being spent in actually supporting the child.

Parents often get the impression from schools that their children are a burden on the school and that other school money has to be spent on their child.

There is a perception that seems to be founded in truth that students in Catholic and Independent schools are allocated fewer resources, in dollar terms, than an equivalent child in a DET school. If this perception is true something needs to be done to address this inequity - if it is not, having a more transparent system of resource allocation will put parents' minds at ease.

Individual Learning Plans

More accountability is needed in the area of Individual Learning Plans. Many parents report that a plan is presented to them when they come to the ILP meeting, rather than being developed collaboratively. Even though parents are usually given the opportunity to add other goals many parents feel intimidated when presented with a virtually complete document.

ILPs are often not completed during first term. Parents report that they may have to chase the school for the meeting. There does not seem to be any accountability on the part of DET schools to actually make sure that these meetings are held. On other occasions when the school plans the meeting too little notice is given to parents and there is no flexibility in times offered, which may mean that working parents are not able to attend.

Finally often plans are too long to be a useful working document - shorter ILPs with achievable goals and reviews each term by parents and teachers would mean that a useful, working document could be developed and amended throughout the school year. The goals need to be specific. For example "Greet a friend and play with him for 10 minutes at lunchtime" rather than "Encourage better social interaction". Currently parents report that ILPs are written and then appear to be put in a drawer and not consulted again for several terms.

Learning Support Assistants (LSAs)

Frequently the neediest children in a school receive their education from the least qualified members of staff - many students with disabilities are actually taught by the untrained Learning Support Assistants / Teacher's Aides who are employed to support the teacher with the child rather than to actually teach the child.

Learning Support Assistants employed by DET currently do not have to attend any pre-service training, and may thus arrive to support a child without knowing anything about the child's medical or educational status. Obviously there are issues of privacy involved but knowing how the child learns best, how to manage behaviour etc even if only in a fairly general way would seem to be mandatory.

Most LSAs are worth their weight in gold but many still struggle with their actual role - being there to support the child when and where necessary and not to smother or own the child. The later type of LSA, the "Velcro aide", is unfortunately all too common.

The concept of the LSA being a *coach* seems to be underutilised. The LSA who was worked him/herself out of a job is frequently the most effective LSA, e.g. a highly disorganised child may no longer need help to get books for the school day if their LSA has taught him/her the necessary organisational skills and set up the necessary visual reminders.

It is essential that time be allocated for teachers to meet formally with LSAs to plan and evaluate for the children in their care.

Inclusion Support Staff

The current model being used in ACT Government schools is difficult to fathom. Some of the staff believe that they are not "allowed" to have any direct contact with parents and their dealings are solely with the teacher. This blinkered approach flies in the face of creating positive partnerships between parents and schools. The inclusion support staff member is a critical member of the team that case manages ASD students and restricting their input to attendance at two ILP meetings a year is ludicrous. In many instances parents are totally unaware of who the Inclusion Support person is at their school or what their role is. Conversely many parents report that the Inclusion Support person is almost totally unaware of the needs of their child. Some inclusion support staff have even admitted to "not knowing the child very well". It seems in everyone's interest to have a clear idea of who does what in each school setting when overseeing the complex needs of ASD students. It appears that only students and teachers experiencing high levels of crisis are given any attention. Everyone else is given lip service. If this is a budgetary issue related to funding allocation then greater funding should be given. The inclusion support staff should be a team of teachers who have great expertise in providing mainstream teachers with ASD strategies and whose role it is to help in crucial periods of transition. This is not happening in many cases.

Collaboration with parents and carers

Many Autism Asperger ACT members find collaboration with schools challenging and frustrating; and at times communication between the two parties totally breaks down.

Many schools are *school centred* not child centred and these schools do not encourage parents to take an active role in their child's education. We do, of course, acknowledge that schools have a curriculum to teach and many other children for whom they have provide an education. However, they seem to miss the core issue which is the child is part of a family and that what happens at school impacts on home life and vice versa. In addition the family have a wealth of information on their child that can prove invaluable in the classroom.

Parents of high school students talk about the frustration of having to work through Year Coordinators rather than talking with teachers directly. Time allocated at the parent-teacher evenings is far too short to discuss the needs of any student never mind the complex needs of a child with a disability.

Partnership with the tertiary sector

Autism Asperger ACT agrees with Professor Shaddock's ideas to involve students from the tertiary sector in schools as part of their practical experience while doing their courses. Having students in classes would provide additional personnel to assist the children and the teaching staff. Projects on individual children (with parental permission) would provide an opportunity to look at an individual's learning style, communication, play and social skills etc, in a more comprehensive way than a teacher with a number of children to educate is able to do.

Other issues

Transport provision to and from special settings (special schools, units and centres) is a great cause of concern for our parent members. Some children, especially those furthest away from their school spend an hour or more travelling each way to and from school each day. Children who have to travel this length of time have to get up very early in time to get dressed, toilet and have breakfast (all usually quite lengthy processes for children with a disability) before the bus arrives and are thus not in the best frame of mind for optimal learning.

Lack of adult supervision on some buses is also a concern for parents.

Parents also report that some difficult children have been refused transport thus adding to an already over-burden family's load.

Planning and accountability

Autism Asperger ACT strongly urges more planning for the future needs to be given while the student is still at school.

Black Mountain School has recently started to talk to parents of students as young as Year 7 about plans for the future - for many families planning for the future for a person with a disability takes time.

More accountability by schools to DET re timely completion of ILPs, Review Meetings and resource allocation is needed. Personnel in Students Services have often been unaware of ILP meetings not being held in Term 1 unless informed by parents or Autism Asperger ACT. A great deal of money is provided by DET for the support of students with Autism Spectrum Disorder in schools and yet there seems to be extremely limited accountability on the schools' part for these additional resources.

DET needs to put into place a *specific team to manage students refusing to go to school (school refusal)* - a significant problem for adolescent students with ASD. Serious consideration should be given to *establishing a high school specifically for children with ASDs*. The high school years are especially trying for our students who regardless of their level of intellectual ability always struggle with the social agenda of other adolescents. The large, busy high school environment frequently induces a high degree of stress in students with ASD.

Social Skills Training

Currently social skills, the core deficit in Autism Spectrum Disorder are not taught in a structured systematic way at schools. Parents do their best but social skills should be taught in the social environment and for students aged 3 to 18 years it is school. Members of Autism Asperger ACT would like to see a specific autism friendly social school agenda be introduced into all schools for children with an ASD.

Early Intervention

Although Professor Shaddock and his team did not have a mandate to address preschool services, and particularly Early Intervention the waiting lists and inequity of service in this area are shameful.

Children attending an Autism Intervention Unit receive appreciably fewer hours in their preschool year than a child without problems who attends his/her local preschool. Although the child with an ASD can make up the hours in a mainstream preschool and may even be allowed to attend both groups for up to 20 hours a week, for many children with ASD local preschool is not an appropriate learning environment and may in fact be detrimental due to high levels of stress on the child's part. Parents of these children who reluctantly decide not to send their child to the local preschool setting are completely perplexed as to why their child with a recognised and severe disability is only offered 8.5 hours *appropriate* education a week while a mainstream child receives 12.5 to 15 hours a week.

Training of teachers for units is another issue of concern. Teachers have been placed in the Communication and Social Awareness Group, for children between 2 and 3 years of age who are suspected of having an ASD and Autism Preschools (Autism Intervention Units) without even a basic introduction to Autism Spectrum Disorder - this is totally unacceptable. If trained teachers are not available the new teacher should be given the opportunity to team teach in a similar setting for several weeks and then should be paired with an experienced mentor.



Autism Asperger ACT has been pleased to be part of this review process and trusts that this review will actually result in positive changes for students with disabilities in all ACT.

Please contact me should you wish to discuss these issues further.

Gay von Ess

President

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