

Support Groups Survey Questions for ASD Parliamentary Inquiry

There are seven areas being investigated. Please read through all of the following sections. I don't expect that you will have a response to each question, so only answer those where you feel that you have useful input.

To respond, simply start typing on the line just below the relevant question(s). Save the document and send it back to me by email.

I understand that this document is lengthy and a bit tedious to work through, however this is YOUR chance to have input into the services and supports provided to you by the various levels of Government and other service providers.

Some questions refer to "your children". If you have children, then you're well placed to respond to these questions if they apply. If you are under 30 and have had relevant experience, you can use yourself in this case. If you are over 30, then your own experience is probably too long ago to be relevant.

1. Availability and Quality of AS Services

The following questions are about services provided for AS children and AS adults, as well as families and carers (including siblings, parents, spouses and children of those with AS).

1. What is your experience of accessing services, information, advice and support?

Harder to access services in Ballarat as generally weren't available especially early on. (I.e. 1-2 years ago)

2. What is the quality of these services, the standard of advice and the reliability of information given on AS?

Most of the presentations we have attended have been really good, but there is a lot of repeated info and they state the obvious which is unhelpful when we have to move heaven and earth to get babysitting and travel long distances to attend etc.

One course that we attended in Balarat in 2013 known as Talkability the course presenter rushed over the information, so we found it to be a waste of time attending. The presenter talked at a miler a minute and brushed over the info. They also (for some unexplained reason) were able to charge us double compared to non-HCWA funded families for the same course (> \$3, 000) which resulted in us not having access to HCWA funding the following year when our ASD daughter attended prep and was subsequently without help from specialist services including the OT during the crucial time of school transistion. Looking back we would have forgone doing the Talkability course which we didn't gain much knowledge from and didn't help us mainly due to the teachers unhelpful teaching methods.

3. What is the quality of the support provided?

We found our OT to be really good in her approach to helping our daughter wither methods and conversing with the education providers including Kindergarten and school transition. But unfortunately that's where it ended.

4. What issues do you experience with parenting of your children with your AS partner, especially issues with your young children?

Frustration dealing with behavioural issues including the restrictive diet of our ASD child and her not listening to following instructions and sometimes still running away.

5. What is needed to support AS parents and their spouses to ensure the needs of their children are met?

More social opportunities for the child / parent/s especially when the ASD child is younger. We find we still don't get out much ourselves of which there are a few reasons / issues including fact neither of us live close to where we grew up nor do we have parents (mine have both passed away in last 10 years) nearby to babysit has meant we were unable to attend social functions very easily.

The other issue is when we do take our ASD child to social events we often end up having to leave almost straight away or spend the time watching her instead of socialising ourselves. The main reasons for this include that the food on offer is unfriendly for our ASD child (who is on a FOOD MAP diet) to eat and will exacerbate her ASD behaviour if she happens to eat it.

Even ASD organisations and ASD events provide mainly food that's ASD unfriendly which we find most odd. We have also found during preschool and even now at school that our daughter doesn't get invited to many birthday parties of her class mates.

I found ASPECT who provided a dads social dinner and learning session a few times to be a good outlet for myself and I also found a dads support group for dads of children with disabilities who meet at a venues for dinner each month to be really good, but haven't been able to attend past couple years due to baby- sitting and financial reasons.

Two years ago we found Pinarc in Ballarat were able to arrange funding for us have someone come from Homecare Plus once a month to look after our two children while we have some respite which has been really helpful to our relationship..

2. Health Services

These questions relate to health services which you might access for yourself, your partner or your children. This might include your doctor or any other service related to your health.

1. Does the health system provide adequate access, information and support?

2. What is the accessibility and availability of quality assessments and diagnoses of Aspergers for AS children?

From listening to other families talk about this I feel like we were lucky to get our child diagnosed by the age of 3 / 4 years. Its costly and time consuming for families with appointments with specialists and paperwork.

3. What is the accessibility and availability of quality assessments and diagnoses of Aspergers for AS adults?

I had to pay ~\$500 dollars three years ago for my own diagnosis as out of pocket expense.

3. Disability service providers

While many of us do not accept that we are "disabled", many still receive Government support under disability services. You can comment on your experiences of these services here.

1. Does the disability service sector provide sufficient and quality tailored services to people with AS?

2. How well do these services meet your expectations?

4. Education

These questions relate to your, or your kids' education. The first is rather general, while there are some examples to prompt your thinking under the second question.

1. Do you consider the education needs of those with Aspergers are being met?

I feel that in the catholic school system they are more than at government schools. Our ASD child has had a teachers helper the past three years and I believe it's due to their being other children with learning difficulties in the same class and year level etc.

2. What are the resource limitations, and what are your suggestions of what we need?

For example: social skills training in school, ability of your chosen allied health to work with your child in the school (currently some schools limit who can do this), specific support in weaker subjects, VCE exam consideration for extra needs to ensure exams reflect capability e.g. more time, computer use, compulsory teacher training in managing ASD needs included in annual training requirements (currently not compulsory in training), curriculum which can include special interests of ASD kids, support of tertiary students with ASD so they can manage the lack of structure and complete tertiary studies.

Our HCWA funding wasn't available to us for (reasons stated above) so we didn't have an OT available to attend our home or school during our ASD daughters prep year which saw our ASD child suffer in that year by not being able to attend full school days until near end grade 1, plus falling behind the other children in her class and lack of social skills help.

5. Workforce issues

1. What training is needed for workers in AS related services to ensure informed, compassionate, and professional services are available to people with AS?

For example: training for teachers, doctors, psychologists, relationship counsellors, employers?

Teachers absolutely! Thankfully our ASD child's teachers have been really good with her needs and integration into the class room.

We did however have to inform and refer the schools teachers to ASD transition days etc which they weren't aware of but fortunately did attend.

6. Impact of NDIS

NDIS is the National Disability Insurance Scheme. These questions seek input into how well the Scheme is working and how it may be improved.

1. Are you concerned that those with AS will receive even less support under the NDIS?

Not in our area yet.

2. What gaps can you see for your family in what you need compared to what the NDIS will provide?

3. How could the NDIS be improved?

7. Community participation and Employment

These questions relate to your participation in the workforce and as a member of the community.

1. What issues do you face with gaining and keeping employment?

I'm currently unemployed due to fact I selected and trained for a career about 10 years ago that requires someone who can handle people in not so nice situations and make them do what is required under sometimes weak legislation. I.e. My work requires excellent negotiation conflict resolution skills which I can find challenging even at the best of times. So after resigning from a stable job in a busy regional city due to complaints made against me from a few difficult clients and my employer threatening me with an official warning;; I have had to rely on filling contract positions in rural locations where the work staff and community are generally more appreciative of me being there.

I'm now less able to take on these type of roles due to family commitments before and after school especially now that my wife will be working in a fulltime position beginning next month.

2. What do we need to ensure inclusion of those with AS in our skilled workforce?

For example: specialised help with career choice for those with AS, training in behaviour for job interviews, managing your colleagues, working in teams, accommodating sensory issues? Clear guidelines on unsuitable careers but with lots of examples of alternatives.

3. Have you or your AS family members had problems communicating with police when encountering the justice system?

Luckily none of these issues to date.

4. MET conductors or other officials?

5. sports coaches or other activity leaders?

6. How serious were the consequences: avoidable incarceration, meltdowns, fines incurred?

7. Do we need training in AS awareness and communication for police, MET conductors, sports coaches and others?