

**Submission
No 17**

**INQUIRY INTO ECONOMIC AND SOCIAL DEVELOPMENT
IN CENTRAL WESTERN NEW SOUTH WALES**

Organisation: Rural and Remote Autism Spectrum Disorder Awareness and
Carers Network

Date received: 25/08/2011

Rural and Remote Autism Spectrum Disorder Awareness and Carers Network submission



(Parliamentary submission report to support the need to establish and maintain a rural and remote carers' network service and research group tasked at looking at future service provision)

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Prepared for the:

“Standing Committee on state development“

(Inquiry into economic and social development in Central Western New South Wales August 2011)

What is needed for families living in NSW and rural and remote Australia who are dealing with the complexities of ASD?

**Why is this support needed?
And what will the proposed committee / network support provide?**

Contents

- Contents Page Page 2
- Executive Summary Page 3 & 4
- Why is there a need for this submission? Page 5
- What is ASD? Page 5
- What are the difficulties that people with ASD face? Page 6,7, 8 & 9
- How can the committee and the network support reduce these difficulties? Page 9,10,11,12
- Recommendations Page 13
- Submission granted (Next steps) Page 14 & 15
- References Page 16

Executive Summary

It is hoped that this submission report, its findings, conclusions and recommendations' will be viewed favourably by the "Standing Committee on state development" and endorsed as such so that the proposed specialist committee can gather data and then be charged with establishing and working jointly with the network group providing support and improving access for rural communities in Australia; managing the problems associated with living and loving those on the Autistic Spectrum on a daily basis.

Whilst it is not disputed by the group that there are other Autism associations providing support across the Australian States; it is accepted and viewed by the users and their families that the services provided are of an ad hoc nature and vary greatly depending on where one lives. This postcode lottery of services does not offer a consistent approach to support, advice which will benefit all or the management of ASD problems or medication.

It is also widely accepted that carers of those with ASD have very different needs when living in rural areas than those living in cities where help and advice and other services are more easily accessible and the population is higher per square metre. It is also recognised by professionals that the data available for the whole of New South Wales (NSW) surrounding diagnosed ASD conditions is hugely understated and that there are more people than ever budgeted for or recognised within the previous service budgets; so that there is a huge gap between demand and sustained provision. The direction of the research needs to look at all of NSW as well as the priority area of the network support group; the rural and remote parts.

It is hoped that the successful establishment of the committee will help support the network group for families and help shape future service provision across the sectors in this geographical location. The network which has been set up by the Directors and writers of this submission is in its infancy; when the committee is established it is hoped that it will be multi faceted and the support network and committee will work together to have a multi disciplined approach to resolving issues and obstacles for those with ASD and their carers.

Service users: those affected with ASD and their carers will have access to an overarching support network and a wealth of advice and sharing which will provide for families living in rural and remote areas dealing with the complexities of Autism (ASD) and its spectrum by providing a consistent and streamlined service platform to begin delivering what is needed for this specialised, under diagnosed, invisible community. From here the committee and support network can make suggestions and implement models of care for those with ASD and their families by tapping into public, private and voluntary funding streams to provide what hopefully will become a model of care replicated by other areas in the future.

However, in order to allocate any new services most efficiently, further research is required and to this end, it is recommended that a Rural NSW ASD Committee be established.

The mission of the Committee is to best serve the interests of those members of the rural community who are affected by ASD (individuals with ASD, partners, carers and families).

The mission statement of the committee is to improve the rural community's access to ASD specialist services. The focus of the committee will be on gathering information, designing research and analysing data related to ASD in rural NSW in order to be able to design a multi discipline model of care and support by answering the following questions:

- **NEED:** Quantitative assessment of the demand for ASD specialist services across rural areas of NSW.
- **LOCATION:** Where best these ASD specialist services should be geographically located in order to improve access in those areas of need i.e. Wellington NSW.
- **FUNDING:** How to attain the funding to provide the infrastructure to develop these services including the Rural and Remote Autism Spectrum Disorder Awareness and Carers Network.

And in doing so the committee will highlight that there is an invisible layer of those with ASD and their families and as a result the demand for ASD services in the rural community is understated!

Why is there a need for this submission?

The intention of this submission is to ask the "Standing Committee on state development" to establish a Multidiscipline Committee charged with improving access of rural communities' access to Autism Spectrum Disorder (ASD) specialists' and then going on to support the network to provide the services that are missing.

The submission has been written by Mrs Betty Ross and Ms Aimy Thorne and will highlight why a multidisciplinary approach to information gathering and the network support and the need for the two entities to work together for and on behalf of this geographical area is desperately needed.

For this submission and ease of reading Autism and Autistic Spectrum Disorder will be addressed as ASD.

What is ASD?

ASD is Autism Spectrum Disorder (ASD) is a term commonly used to refer collectively to Autism, Aspergers Syndrome and Pervasive Development Disorder – Not otherwise specified (PDD-NOS).

The American Psychiatric Association, 2000 cites that *'In general, the characteristics of Autism Spectrum Disorders (ASD) are primarily associated with impaired development of social interaction and communication skills. Individuals with ASD also demonstrate restricted repetitive patterns of behaviour, interests or activities'*

However it is much more complicated than this and cannot be so neatly boxed; these abilities present themselves with different severities in each individual, which has led the disorder to be conceptualized as existing on a spectrum, which is the autism spectrum. The autism spectrum ranges from severe social, communicative impairment and related issues (such as Classic Autism) to social, communicative impairment and related issues (such as Aspergers Syndrome).

Some people with ASD have neuro-developmental disorders that sit on the milder end of the spectrum and sometimes people can refer to this as Aspergers Syndrome. It is characterised by particular deficits in social/emotional reasoning skills, a narrow range of interests or a 'one-track- mind', and often by motor skill and sensory problems. People with Aspergers Syndrome can experience discomfort in many social situations, increased levels of stress after social situations, and discomfort with certain sensory stimuli. They often have a different way of solving problems, an obsessive approach to work and interests, and difficulty picking up on social clues. Difficulties with short-term memory, planning, taking the initiative and prioritising are also common features of this condition. Autism is a lifelong developmental disability that affects how a person communicates with, and

relates to, other people. It also affects how they make sense of the world around them.

As ASD is a spectrum condition, it means that, while all people with autism share certain difficulties, their condition will affect them in different ways. Some people with autism are able to live relatively independent lives but others may have accompanying associated disorders such as learning disabilities and mental health problems and need a lifetime of specialist support. People with autism may also experience over /or under-sensitivity to sounds, touch, tastes, smells, light or colours. Many people on the ASD spectrum have other co morbid disorders' which makes diagnosis and management of all the conditions hard for the specialists involved and their carers.

Those with ASD have often been diagnosed and treated incorrectly with disorders such as schizophrenia and other personality disorders.

When the term ASD is mentioned within this report it will include all forms of Autism and its "associated conditions" including but not limited by Aspergers Syndrome and Pervasive Development Disorder (PDD).

What are the difficulties that people with ASD face?

The Directors of: "*RURAL AND REMOTE AUTISM SPECTRUM DISORDER AWARENESS AND CARERS NETWORK*" have established the support network, the website and the social networking groups as direct derivative of a real need coupled with the demand for needing to share experiences by other carers of ASD in rural and remote areas. To date the group has attracted members as far west as Broken Hill 800km from where the Directors reside in Wellington NSW and Molong NSW. Due to the lack of availability of services we have established the above mentioned network and it is thriving with people wanting more and more support.

The Directors have contacted "ASPECT" on several occasions requesting information and assistance. On one occasion they were advised that they did not provide their services to rural and remote areas and in particular for adults.

A request for up to date statistical information has been placed but to no avail; still awaiting the information they advised that they were going to send.

Given the apparent lack of data from "Aspect" information has been sought internationally from the National Autistic Society in the UK where the prevalence of Autism (ASD) is a recently much debated subject and where ministers for health have recognised the invisible under-diagnosed group and the increasing prevalence rates of ASD and have sought to introduce the Autism Act 2009 which has helped define the economy, focuses on those with ASD, allows carers to be able to work, provides support and lessens the strain

on other public services which happen as a direct result of lack of support for these families.

- Autism is a serious, lifelong and disabling condition. Without the right support, it can have a profound - sometimes devastating - effect on individuals and families¹.
- Autism is much more common than many people think. There are over half a million people in the UK with autism - that's around 1 in 100². If you include their families, autism touches the lives of over two million people every day
- Autism doesn't just affect children. Children with autism grow up to be adults with autism³.
- Autism is a hidden disability - you can't always tell if someone has it⁴.
- While autism is incurable, the right support at the right time can make an enormous difference to people's lives⁵.
- Over 40% of children with autism have been bullied at school⁶.
- Over 50% of children with autism are not in the kind of school their parents believe would best support them⁷.
- One in five children with autism has been excluded from school, many more than once⁸.
- Nearly two-thirds of adults with autism in England do not have enough support to meet their needs⁹.
- At least one in three adults with autism are experiencing severe mental health difficulties due to a lack of support¹⁰.
- Only 15% of adults with autism in the UK are in full-time paid employment¹¹.
- 51% of adults with autism in the UK have spent time with neither a job, nor access to benefits, 10% of those having been in this position for a decade or more¹².
- 61% of those out of work say they want to work¹³.
- 79% of those on Incapacity Benefit say they want to work¹⁴.

Although the demographics and social dynamics and funding for treatment and support differ greatly in the UK compared to the rural and remote areas of NSW Australia; when coupled with the statistics available from the nearest specialist centre for ASD which is in Sydney it is familiar, frightening picture to see the full extent and impact Autism (ASD) has on its sufferers and carers.

As Directors of the support group the nearest access to treatment for our ASD others and ourselves is in Sydney and can only be accessed fortnightly and monthly respectively, this is due to a lack of skilled Clinical Psychologists trained in the treatment of ASD, and skilled Sensory technicians to deliver treatment in the public or private sector in country NSW.

For children aged from 5 to 7 they are funded through the 190 million dollar 'Helping Children with Autism Package'. For adults there is no such help. The amount funded through this package amounts to \$12,000, \$6,000 to be allocated per financial year, then funding ceases. This funding can be used for Occupational, Speech, Psychology Therapy, also approved aides but once

funding reaches the ceiling if treatment is to continue it must be funded by the family themselves.

After the child reaches the age of 7 unless the parents are wealthy there is minimal intervention for the child. Therefore all the funding provided prior to age 7 has been wasted as there is no means to carry on and the child will regress or stay at that stage of growth.

As there is no ring fenced funding for adults with ASD this comes at a great family cost at \$750 per fortnight. This includes travel expenses, accommodation, meals, tolls and fees just to see the Clinical Psychologist. This is unsustainable in this economic climate for any 'typical' family.

Under a policy which is due to expire on November 1st 2011, Medicare will refund 75% of the schedule fee for 12 visits and 6 more for special circumstances to a Clinical Psychologist or Psychologist. After November 1st 2011, the Federal budget has cut the visits to 6 and 4 more for special circumstances. Clearly showing that there is a gap in provision; when dealing with Autism there is no one size fits all.

In a family where each member has to access a Clinical Psychologist for treatment because of the trauma caused to each individual member of the family who is living with an ASD other this is a backwards step and a recipe for disaster.

It is already known that:

- 80% of ASD marriages involving an ASD child or partner end in divorce
- 80% of ASD people fail to maintain employment
- 60-70% of Incarcerated people are on the Autism spectrum

The Australian Advisory Board has recently undertaken some research and have tried to look at the provision of services and diagnosed figures relating to those that they know are diagnosed and looking at the invisible group that they know exist but have not reached yet. As an advocate of ASD they cite that there should be a national protocol of no more than 3 months waiting time for a diagnosis and assessment by multidisciplinary teams who are funded to provide these services.

In reality the report found that things were quite different:

- *The core finding of the report could be extrapolated to suggest that with a prevalence rate of 62.5 per 10,000 there could be as many as 125,000 people with ASD in Australia or 500,000 Australians in families affected by ASD.*
- *This figure does not include adults who have been misunderstood and are caught up in the mental health system nor does it encompass the understated number of girls which are under diagnosed (This adds to incomplete data not giving a true representation of the figures)*
- *A prevalence rate of 39.2/10,000 for all ASDs was established which represented a 10 fold increase in the rate of ASD diagnosis in the area*

over the past 16 years. Male/female ratio was 8.3:1. and age at diagnosis ranged from 2.3 years to 16.3 years

- *Waiting times for diagnosis for up to 24 months across the country*
- *Difficulties in rural and remote areas*
- *Costs incurred by families in the private sector need to be known to give an accurate understanding of the costs of caring a child with ASD.*
- *In Victoria the peak ASD body represents 12 specialist autism providers covering all age group.*
- *Government departments do not provide funding to individuals with a diagnosis of PDD-NOS and no data about this diagnostic group were available.*
 - *Access to timely and affordable diagnosis*
 - *Early intervention for pre-schoolers*
 - *Early schooling*
- *Improved data collection methods and consistency in diagnostic procedures when looking at co morbid conditions*

In addition to the report findings professionals note there is a hardship at diagnosis; as is at families own expense (so many will not bother to get diagnosed but problems still exist for them and the carers), also some people get treatment from the private sector in metropolitan areas so these two groups form part of the invisible layer.

How can the committee and the network support reduce these difficulties?

While ASD is a life-long profile of abilities that is usually evident in early childhood it is possible to reduce the impact of these difficulties. For example, as many individuals grow older, they are able to use their intellect to develop compensatory strategies for things that come to them less naturally, for example social skills and perspective taking. In addition, through specialist therapy specific skills, strategies and support can be taught and implemented to help the individual cope with their unique ways of experiencing the world.

It is evident that individual's with ASD can experience a range of unique difficulties as they transition into different phases of life. In addition, the presentation of ASD varies greatly and therapy that works for one individual will not always work for another.

Further, it is common for many individuals with ASD to also present with separate but co-existing disorders such as anxiety, depression, attention deficit/hyperactivity disorder, nonverbal learning disorder, motor clumsiness, obsessive compulsive disorder, Tourette syndrome and a range of sensory related problems impacting behaviour

It is because of the breadth and complexity of difficulties individuals can encounter across their lifespan that psychologists or psychiatrists who specialise in ASD are best suited to assist them overcome their specific

challenges. Support is paramount because lots of evidence based research is showing that the carers of people with ASD are suffering just as much.

The new committee and support group network would like to work towards a future goal of introducing consistent sustained services where families living in NSW could be offered a clinic type facility with a multi disciplinary approach that they could access to help manage their ASD and seek support. This is a future consideration but one that should be borne in mind when looking at future provision for this community.

- Borne out of the report, the committee / group / support can enhance this project tenfold by offering a multi disciplinary approach for those with ASD and their families.
- Government's own Centrelink data, the core finding is that there is an estimated prevalence of autism spectrum disorders across Australia of 62.5 per 10,000 for 6-12 year old children
- Currently there are two sources of national data about autism, Centrelink and AIHW (CTSDA-NMDS data), that were able to provide information to this study
- Support should be made available to guard against additional mental health deterioration of carers.
- All research to date demonstrates that early intervention leads to better outcomes for children with an autism spectrum disorder. After the age of 7 there are minimal ASD Psychology services in rural and remote areas, other ongoing continuing factors:

Funded research by the committee coupled with the right support for those highlighted through the research will result in the following:

- Enhanced economy through employment opportunities when ASD families are supported
- More Speech Therapy
- Sustained Occupational Therapy
- More Sensory Therapy
- Better Education chances
- Better diagnostic tools
- Early intervention

Early research by the Directors show that in rural and remote communities there are large indigenous populations and diagnosis and intervention is not being accurately recorded.

At least one agency from each State or Territory (not including the ACT) provided information about families living in rural or remote locations with children with ASD, with percentages ranging from 12% to 39%.

Upon consultation with Mr Steven Den-Kaat, Director and Clinical Psychologist from "Embracing the Other Half of Psychology Clinic", Sydney NSW. Mr Den-Katt provided the following statistics from his clinic.

- 175 New Clients in 2011 who required individual therapy related to ASD e.g. could be individuals with ASD or their partners and parents etc.
- On average 175 / 7 months = 25/month, average 4 a week across 4 soon to be 5 Clinical Psychologists.
 - Some of these clients are for one-off diagnostic assessments
 - And some continue with ongoing therapy either weekly, fortnightly or monthly.

Mr Den-Kaat Statistics only

1. Geographic Areas of Mr Den-Kaat's clients attending an initial 2-hour diagnostic assessment from January 2011

Geographic Location	Number of Clients	Percentage %
Sydney (less than 2 hours from ETOH)	29	63.0
Outside Sydney (2-4 hours from ETOH)	3	6.5
Greater NSW (more than 4 hours from ETOH)	8	17.5
Interstate	4	8.66
Overseas	2	4.33
Total	46	100

This year within Australia, we have seen clients from Greater New South Wales, ACT, Victoria, Queensland and Far North QLD as well as Western Australia, Northern Territory and Tasmania.

Worldwide, we have seen clients from New Zealand, Italy, England as well as Hong Kong and Singapore.

2. Geographic Areas of Mr Den-Kaat's clients attending ongoing therapy at present.

Geographic Location	Number of Clients	Percentage %
Sydney (less than 2 hours from ETOH)	20	51
Outside Sydney (2-4 hours from ETOH)	8	20
Greater NSW (more than 4 hours from ETOH)	8	20
Interstate	3	9
Overseas	0	0
Total	39	100

Descriptively, this means seeing clients from all over the Sydney metropolitan area, as well as North Coast, Central Coast, Sutherland Shire, Blue Mountains and Greater New South Wales such as Tamworth, Dubbo and Wagga Wagga. Interstate includes ACT and QLD.

3. Because of the large geographical distances that clients have to travel, Mr Den-Kaat has been using Skype or telephone consults on a 1:1 ratio

with face-to-face therapy sessions. This can halve the impact of travelling several hours by train and car and reduces the cost of expensive plane tickets.

Therapy	Number of Clients	Percentage %
Purely Face-to-Face sessions	32	82
Combination of Face-to-face and Skype/Telephone	7	18
Total	39	100

(For further clarification on any of the supplied data, contact Mr Steve Den-Kaat, Director and Clinical Psychologist of Embracing the other Half).

The pictures that the precluding tables show and this is echoed internationally with the figures from the UK is that there is a rising number of ASD sufferers and their families especially within the rural and remote areas of Australia.

One needs to bear in mind that these figures are greatly understated as those that are accessing services are the visible ones but for every ASD person identified there are many more suffering with the same problems but they are invisible to services and may be misdiagnosed.

The prevalence of Autism has always been hard to estimate and has always been seen as a rare condition but more information about the possible number of people with autism in the community based on epidemiological surveys (i.e. studies of distinct and identifiable populations) shows the prevalence to be a lot higher than first thought. Boys it appeared were more likely to have Autism than Girls but world leaders such as Associate Professor Tony Attwood express that this is no longer the case and at least one in four girls have the condition as well; girls with ASD are another layer that before now hadn't been a part of the invisible layer.

It could be argued that this gap has existed for a long time and that ASD has been there under diagnosed and that families have coped; whilst the Directors acknowledge this; medicine has advanced to a more proactive "well being model of health". Tackling problems before they become worse and manifest themselves in other services is a clear cost efficient model for health than waiting, for example: if no support is given then there is a larger stress on other services and the negative impact it has on the economy with sick days and the effects on the mental health of the carers /other family members; this lack of support breeds other problems which would have been initially more manageable if support was provided initially.

Recommendations

The ultimate goal of this submission is to show that carrying on without support in this area is not sustainable and needs immediate address.

This submission paper has only scraped the top of the problem and the "Standing Committee on state development" needs to give the go ahead to this submission to task the committee and support group to do more research to show the full extent of the waiting time bomb this community faces.

The committee need to work in unison with the support network in order to start to provide a stream less service for a diagnosis for visible and invisible sufferers of ASD and their carers.

The work of the committee and support group will enhance the quality of life of these groups of rural and remote ASD sufferers and their family. It will bring to the people what is needed and the group will serve to create the right model of support what will in turn result in:

- Stronger carers
- Reduced mental health issues on all family members including extended family
- Less strain on the economy
- Increased strengths for the ASD / AS people
- Better communication
- Timely Diagnoses
- Consistent levels of care and support
- Multidisciplinary approach aids all areas for the ASD person and the family
- More holistic approach
- Less stress on other public services like health care, police etc.

If endorsed by the "Standing Committee on state development" the submission will be allowed to start work and the arguments for why the support is needed will be strengthened through additional research.

The Directors have identified some voluntary funding pathways for this particular piece of work and that of supporting the network group but a specialised ring fence budget is what is needed.

The idea of further research and the support group and ring fenced funding has already been endorsed by the Honourable Andrew Gee MP, Steven Den-Kaat, Director and clinical Psychologist of Embracing the other Half, Sydney, Technical Aid to the Disabled (TAD) Northmead Sydney, Wellington Times Newspaper- Rural Press and Commonwealth Carers respite Centre, Dubbo. As they have embraced and recognised the need for such a group.

Currently there are additional money pots available from local government which families can access to help them seek help and an example of this is

the FaHCSIA for rural and remote communities needing to travel for treatment. However their eligibility criterion does not include ASD as Director Aimy Thorne found out when her application was denied recently. The criterion for this funding and its application process needs to be looked at and revised to allow ASD families to get the same help as other diagnostic conditions.

Submission granted / next steps

The Directors of this group and writers of this submission would be more than happy to come and verbally avail the committee of any further clarification if this was needed.

Once approval and funding has been granted the next steps would be as follows:

1. Establishing a Committee charged with improving access of rural communities access to ASD specialist services.

The report highlights that there is a significant demand for ASD services, in the rural community. However, in order to allocate these services most efficiently, further research is required.

To this end, it is recommended that a Rural NSW ASD Committee be established. The mission of the Committee is to best serve the interests of those members of the rural community who are affected by ASD (individuals with ASD, partners, carers and families). The mission statement of the committee is to improve the rural community's access to ASD specialist services. The focus of the committee will be on gathering information, designing research and analysing data related to ASD in rural NSW in order to best answer these questions:

- **NEED:** Quantitative assessment of the demand for ASD specialist services across rural areas of NSW.
- **LOCATION:** Where best these ASD specialist services should be geographically located in order to improve access in those areas of need i.e. Wellington NSW.
- **FUNDING:** How to attain the funding to provide the infrastructure to develop these services including the Rural and Remote Autism Spectrum Disorder Awareness and Carers Network.

The Rural NSW ASD Committee should be comprised of a diverse variety of professionals and community members specializing in ASD. This will ensure the breadth and complexity of ASD issues will be considered so that the mission statement is best met. To this end the committee should consist of representatives from:

- Mental Health Profession who have a reputation as a specialist in ASD.
 - Clinical Psychologists

- Mr Steven Den-Kaat has expressed his interest to partake in this role as Clinical Psychologist.
- Pediatricians
- General Practitioners
- Occupational Therapists)
- Rural community members who are affected by ASD as an individual.
 - Parent
 - Partner
 - Carer.
- We wish to fulfill the role of parent, partner and carer.
- Experienced Academic Researchers who have a sound knowledge of ASD and will help design and carry out research to achieve the committee's main goal.
- Government Representatives: To discuss the development and planning of implementing infrastructure to achieve the Committee's mission statement.
 - Department of Education and Training
 - Centrelink
 - Employment Agency
 - Department of Correctional Services
 - Police Department

The Directors look forward to getting the go ahead from the "Standing Committee on state development" to task the new Committee to start this piece of research in the near future and thank you for taking the time to peruse this submission.

References

National Autistic Society Website (<http://www.autism.org.uk/about-autism/some-facts-and-statistics.aspx>)

¹ Rosenblatt, M (2008). *I Exist: the message from adults with autism in England*. London: The National Autistic Society, p3, pp5-7

² Baird, G et al (2006). Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP). *The Lancet*, 368 (9531), pp210-215

³ Rosenblatt, M op.cit. p37

⁴ p37

⁵ p37

⁶ Batten, A et al (2006). *Autism and education: the reality for families today*. London: The National Autistic Society, p3

⁷ p3

⁸ p3

⁹ Rosenblatt, M op.cit. p3

¹⁰ p3

¹¹ Redman, S et al (2009). *Don't Write Me Off: Make the system fair for people with autism*. London: The National Autistic Society, p8

¹² p6

¹³ p32

¹⁴ p6

Steven Den-Kaat, (Embracing the Other Half Psychology Clinic- January to July 2011)

Report from the Australian Advisory Board on Autism spectrum Disorders, "Prevalence of Autism in Australia, can it be established from existing data?"

<http://www.myoutofcontrolteen.com/LivingWithAspergersPartner>