

Committees Parliament of Victoria – Inquiry into Services for Autism Spectrum Disorder

Mallee Family Care Inc is located in the North West Corner of Victoria, bordering NSW and South Australia. There are two main service centres, being Mildura and Swan Hill, covering the Northern and Southern Mallee. Mildura is 4.5 hours' drive from Adelaide and 6.5 hours drive from Melbourne. Accessibility for individuals who have Autism, and supports for their family and carers is often limited in the communities in our organisations catchment areas. Services appear to be available for children 0-6 via Early Childhood Intervention Services, and also assessment and individual therapeutic sessions in Mildura via the Mildura Base Hospital – Clinical Mental Health Service, and individual therapies via Sunraysia Community Health Services. Services outside this age group, and outside this geographical location for high level on going therapeutic treatment and family and carer support is often expensive and inaccessible due to the geographical location (s) of the population base of these areas.

Please note the two experiences described below are representative from across the Northern and Southern Mallee catchment areas.

Early Childhood Intervention Services – By Sherrin Ford – Team Leader.

In recent times (the last three years), there was a surge of people being diagnosed with Autism specifically in the Sunraysia area, with the then Medicare Local focusing on the assessment of people with Autism. This caused a number of issues for people. Whilst some people were relieved to receive a label for the behaviour they had observed for many years within the family unit, others were dissatisfied with the service as there was a lack of follow up of continuous treatment. In addition to this, whilst the then Lower Murray Medicare Local recognised the need for support, the agency failed to work at a community level with other providers of service to re dress this issue.

Diagnosis occurred by fly in fly out specialist. Fly in fly out specialist then provided limited therapeutic intervention. When the Medicare Local transitioned to the Murray Primary Health Network, the Autism assessment work was transferred to the Mildura Base Hospital – Mental Health Services and now sits with the Child Youth and Adolescent Mental Health team, complimenting their already existing service provision.

There are limited opportunities for children to proceed with a diagnosis of autism in the Sunraysia area. The pathways are limited to a free service via the paediatrician and ASSET or a cost of around \$2000 for via private Therapists.

The waiting time to consult with a paediatrician is at least three months and then the paediatrician has to acknowledge there is a possibility of ASD presentation before he/ she will refer to ASSET.

Locally, the frequent experience of parents of young children is that they are sent away from the paediatrician without being "heard" and may have 2-3 subsequent visits before a referral for an ASD assessment is forthcoming.

ASSET is under resourced causing a possible delay of up to 12 months for an assessment to be completed. This delay creates significant anxiety for parent/carers who are seeking understanding of their child's behaviours. This also significantly delays the child's access to Helping Children with Autism funds which can provide early intervention with therapists.

Early Childhood Intervention Services is available to provide therapeutic support to families of children with or without a diagnosis but families can experience a 6-9 month wait for these services.

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Disability services are only available for children with ASD if they have an intellectual disability (ID). ASD has a significant impact on a child/person's engagement in everyday life activities even when they don't have an ID.

The education system is reluctant to adjust its curriculum to include the individual needs of children with ASD. There are substantial challenges faced by families of children with ASD when enrolling and engaging their children in mainstream schooling. Children must have an intellectual disability to enrol in a Specialist School.

Disability Support Services – Peta Lyn Nosatti – Team leader

I have contacted the Swan Hill Specialist School and have spoken to a couple of families who have ASD children and here are some of the responses I received which high light the Gaps:

Gaps:

- More & varied activities/clubs after school
- Supported employment/ employment opportunities in small communities
- Individual Behaviour management support in the home
- Support for siblings
- Support to people who are on the sex offenders register
- Lack of local training for staff to assist with people on the sex offenders register
- Students leaving school from a very structured school environment to attend a day service find the change very challenging. One model does not fit all.

Health Services:

- Assessment required, families travel long distances i.e. Melbourne, Bendigo very difficult & costly,
- Families feel isolates.
- Nurses have lack of understanding on dealing with challenging behaviours when they present at hospital

Integration between services:

My experience is that Service providers Work well in this area i.e. Department of Health & Human Services, Bendigo Health, Employment Agencies, Murray Human Services.

Education and Housing:

- **Education:** Lack of knowledge for teachers at main stream school to assist ASD students in the class room.
- Swan Hill Specialist School appears to have a wonderful reputation

Housing:

- A lack of accessible housing that is going to be safe for people with ASD it has been discussed at length with families they would like a block of units with a care taker to assist in any medical needs, or supervise on any issue that would arise.ie unwanted guests, home maintenance and assisting / prompt consumers with the cleaning of the units & cooking skills.

Work force Issues:

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- All staff should have at least a cert 3 or 4 in Disabilities
- More training is required- add a unit in the all cert 3 & 4 disability courses for ASD specific i.e.; How to manage aggressive behaviour / How to communicate to people with ASD
- Lack of training for employed staff, staff to attend training is normally in Melbourne, very expensive for the casual labour force overnight expenses if needed, pay staff to attend the courses meal allowances etc.

Impact of NDIS:

- More service providers may be available uncertainty for local providers:
- More packages more consumers. The demand may outstrip the skill base required to provide a credible service the suits the varying needs of people with ASD.
- Not enough Qualified & Suitable staff to meet the demand.
- Older work force.
- Young people are not pursuing the industry.
- Older people living in supported accommodation will be transitioned to aged care, this opens up a whole new world and problems, how will the older people cope with very noisy people, hoists in bedrooms.
- How will staff cope with the demands of someone with ASD and other complexities associated with aging? Will the nursing homes meet the sensory needs of people with ASD? What consideration has been given here?
- How will these people manage with the change being removed from people they have shared with for many years and staff that know them very well.

Thank you for the opportunity to contribute our submission to the Autism Spectrum Disorder inquiry.

Cath Murphy
Director of Disabilities and Mental Health Support Services
Mallee Family Care

April 25, 2016.