

**Submission to Parliament of Victoria – Family and Community Development Committee - Autism Spectrum Disorder Services Inquiry**

**On behalf of**

**Echuca Regional Health and Kyabram District Health Service**

Echuca Regional Health (ERH) together with Kyabram District Health Services (KDHS) are pleased to present you with a submission for the Autism Spectrum Disorder (ASD) Services Inquiry.

ERH and KDHS are regional Victorian Health Services within the Campaspe Shire. Echuca Regional Health provides a range of services including, acute, sub-acute, emergency, primary care, aged care, and community health to an estimated population of 44,269, in both the Campaspe Shire and across the border to the NSW Murray Shire. KDHS provide similar services to a smaller population across many rural towns. In terms of ASD provision of services, neither service has any specific funding to provide services for those diagnosed with ASD. However both health services provide clinical services to people diagnosed with ASD across all settings, either as part of their general health care or for specific issues associated with ASD. This is essentially funded as part of community health funding, sub-acute funding or paediatric funding.

KDHS are contracted to provide an Early Childhood Intervention Service (ECIS) to the Campaspe Shire. This service is for children, birth to school age with developmental delay or disability. There is a central intake for this service. The service is known as the Campaspe Early Childhood Intervention Service (CECIS) and works under a keyworker model, empowering parents with support, resources and information to meet their individual needs. Currently the CECIS team consists of Occupational Therapists, Speech Therapists, Allied Health Assistant, Coordinator, and Early Years Educator. In the past, CECIS has also employed Physiotherapists and Social Workers. Within the Campaspe Early Childhood Intervention Service, 14% have a formal diagnosis of ASD, with a further 21% undergoing the process of diagnosis. Echuca Regional Health provides services for children with complex needs from birth to school age within it's community health program. ERH also have a fortnightly paediatric clinic day with a multidisciplinary allied health team approach. This team consists of a Physiotherapist, Speech Therapist and Occupational Therapist, with regular clinical discussions with a Paediatrician. It is estimated that on average 20% of the clientele accessing this clinic would either have or become diagnosed with ASD.

When children are enrolled in school it is the responsibility of the Department of Education to provide services. The service provided by Department of Education is stretched and quite limited. Echuca Regional Health are also contracted to

provide an Allied Health Team (Speech Therapist, Physiotherapist and Occupational Therapist) to the Echuca Specialist School.

Both ERH and KDHS provide assistance with the diagnostic process, although neither have the capacity to make formal diagnosis. The process is significantly daunting and costly for families. Local families need to travel to obtain a diagnosis, and often there are significant waitlists for diagnostic appointments. The diagnostic process can be quite lengthy, and if not visiting an ASD assessment clinic can involve several assessment appointments in different locations, proving to be a lengthy, overwhelming process for families. This is especially the case, if this formal diagnosis is required for enrolment into the Echuca Specialist School. It is more beneficial that a diagnosis of ASD be made by a team of Allied Health Professional alongside the Paediatrician (usually but not limited to a Psychologist cognitive assessment, Speech Therapist language assessment, and an Occupational Therapist assessment).

Moreover, once a family has a formal diagnosis of ASD, and have received their *amaze* (previously Autism Victoria) funding, there is a significant lack of local private allied health practitioners able to provide helping children with Autism services. The lack of private providers means there could be a significant wait list, as well as forcing families to have to travel for appointments again. This can also place extra burden on the public system, as families are choosing to use the public system to access services due to the lack of private therapists in the region. Once families have received their *amaze* funding it is their responsibility to arrange private therapy. Families report that this can be a difficult, overwhelming process. Often families receive their package in the mail, but do not fully understand what it means, or where to next. It should also be noted that in rural areas not all required allied health services are available in the private sphere.

Neither ERH nor KDHS has a funded capacity to provide service to adult clients based on a diagnosis solely of ASD. If a client requires goal directed care, they are eligible for a community health service for short term input. The service is especially limited for adults with a diagnosis of ASD. Those adults residing in our community with ASD can only access our services via a triage system with certain criteria. Examples of appropriate use of community health could be home assessments for safety concerns, mobility and /or transfer assistance, and carer support.

In addition to limited health services for those with a diagnosis of ASD, housing, education, travel, general community services and employment services are also lacking. Locally there are few supported accommodation facilities, with no specialised ASD supported accommodation. Young adults with a diagnosis of ASD are particularly disadvantaged, as they are often housed with the elderly

either in aged care facilities or supported accommodation. Local supported accommodation facilities are not necessarily set up to engage those with a diagnosis of ASD to their fullest potential, and education of staff is sometimes lacking in regards to a diagnosis of ASD. Furthermore respite care for all age groups is extremely difficult to obtain in the local area, further burdening the families affected by a diagnosis of ASD.

Although the Echuca Specialist School accommodates children with 'severe' ASD and/or those with significant 'behavioural issues', the local mainstream schools (pre, primary and secondary) still see several enrolments of children with a diagnosis of ASD. Unfortunately not all the local schools have the facilities, knowledge or skill to accommodate let alone enhance learning for children with a diagnosis of ASD. Additionally, local childcare centers do not necessarily have appropriate facilities and training to accommodate children with ASD. Child care workers may also lack knowledge of potential ASD traits in children, potentially delaying the diagnostic process. There are a few local organisations who cater for people with a diagnosis of ASD, with a focus on respite, carer support, and client support groups. However 'mainstream' community services are traditionally not very good at accommodating for people with ASD. Families particularly struggle with the lack of security for potential absconding clients, lack of awareness, and judgement. Locally, supported employment is limited, with no specific facilities to accommodate those with a diagnosis of ASD.

A common theme expressed from local families is financial burden, beginning from a very young age and extending throughout the lifespan. Families often receive little respite for the care of their children, as appropriate care is not available, parents often become full time carers and are no longer able maintain any form of employment. There are also burdensome costs of therapy, assessments and travel. Families in our community often feel socially isolated, unable to access the community without concerns for safety or fear of judgement, the simple task of visiting a local coffee shop, a park, a movie or a football match can be very problematic for families impacted by a diagnosis of ASD.

Echuca is a border town to Moama, providing services to NSW clients is inevitable, but problematic. The Early Intervention Service in NSW is substantially different to Victoria, and local allied health services across the border are either extremely limited or non-existent. This places a huge burden on Echuca Regional Health's Services. Particularly, if families are accessing schools, childcare, work, community services, healthcare and accommodation across and between the two states.

In the near future, mid 2017, the National Disability Insurance Scheme (NDIS) will be rolled out in the Campaspe Shire. The way that this will affect people

diagnosed with ASD, will differ depending upon their age and the impact it has upon their functional ability. For a child with ASD, they will still be offered a transdisciplinary package with the use of a Key Worker, which will be very similar to the services that they are currently receiving through a CECIS package. At this stage it is unclear exactly how this will look for organisations within our community. KDHS plan to continue to offer these services to the children in the local area. The benefit will be that once the child is funded through NDIS, the service will not have to cease involvement at a critical transitional time, such as heading off to school, but will be able to stay involved with the child and the family, providing services throughout these times. In addition, service provision will no longer be limited to Campaspe Shire specifically; it will be able to offer services across geographical boundaries. ERH continue to investigate where the NDIS will place them, and how we could extend our services with the NDIS.

In summary, ASD is a condition which creates many challenges for those diagnosed with the disorder. Our local area is unable to adequately service those with this diagnosis. There are significant barriers to treatment including delays in diagnosis, travel requirements, access to appropriately skilled clinicians, costs associated with accessing care and a lack of suitable care options particularly for adults. While these are issues throughout Victoria, they are particularly acute regional areas. The population of people with a diagnosis of ASD is continuing to grow, and high quality locally accessible services need to grow with it.

Presented on behalf of Echuca Regional Health, Kyabram District Health Service and our clients diagnosed with ASD.

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