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Inquiry Name: Inquiry into Services for People with Autism Spectrum Disorder

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## SUBMISSION CONTENT:

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Parliamentary Review into Services for People with Autism Spectrum Disorder 2016

This paper is the combined response of clinicians within the Austin Child and Adolescent Mental Health Service (CAMHS) as well as a group of parents of young people with Autism Spectrum Disorder who are clients of the Austin CMHS community outpatient team.
Parents of the group differed from other groups in that their children have high intelligence and were diagnosed later, around age 11. All the young people have co-morbid mental health problems and are clients of Austin CAMHS.
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The paper has been prepared by Liz Morkham, Senior Speech Pathologist, Acting Co-ordinator of the Autism Spectrum Disorder Assessment Program, Austin CAMHS. It is endorsed by Dr Richard Newton, Director, Austin Mental Health Clinical Services Unit; Dr Hanna Cheng, Acting Director, Austin Child and Adolescent Mental Health Service; Mr Patrick O'Leary, General Manager, Austin Child and Adolescent Mental Health Service.
Autism Spectrum Disorder will be referred to as ASD throughout this paper.

Reliability of Diagnosis
Autism Spectrum Disorder is generally considered a developmental disorder with lifelong impacts on social-emotion functioning. Its diagnosis is largely framed developmentally despite being described in the DSM-V, a manual for mental health diagnoses. Interpretation of the criteria for diagnosis is highly subjective and ultimately clinical in nature. Although the statistical results of standardised tools are used to make a diagnosis, their small print always refers to clinical knowledge and expertise overriding statistical results. Consideration for differential diagnosis seems to rely on the experience, knowledge and framework

within which the diagnosing practitioner works. For example, at Austin CAMHS, approximately 50% of adolescents referred over an 18 month period for assessment within the Community Mental Health Team with ASD type behaviours were ultimately diagnosed with other disorders such as Attachment Disorder, Social Anxiety Disorder or Social Communication Disorder. The Autism Spectrum Disorder Assessment programme accepts referrals from paediatricians for clarification of the diagnosis in children aged 3-12 yrs. Similarly between 35 -40% of cases were not given an ASD diagnosis during the 12 months of 2015. These high rates of non diagnosis suggest complex presentations and the need for thorough assessment. The rigour and reliability of differential assessment and diagnosis appears highly variable across the sectors of disability, mental health and private practice where differing knowledge and standards of assessment occur. Assessment processes vary from a single practitioner to multi-disciplinary team assessments with varying degrees of collateral information, ranging from developmental assessments and standardised screening tools being applied. The reliability of diagnosis appears particularly problematic for young people where normal intelligence, more subtle presentations of ASD and mental health problems are evident.

Access to services and information and support

The parent group noted that access to information and diagnosis was a very difficult and protracted process prior to accessing the mental health system. There was no obvious pathway in order to source a diagnosis and all described the process as a maze. The parent group felt that it was hard to navigate different systems and hard to find resources to manage their children in the meantime. The group noted that diagnosis was not a black and white science and they often came up against varying views from different professionals particularly in the private sector, which was confusing.

All the parents reported a long diagnostic journey of about 2-3 yrs, with lack of clarity and long waiting lists for various assessments along the way.

All of the parents noted the expense of obtaining private assessments and private speech therapy or occupational therapy for families. Access to government provision of these services generally ceases or becomes very limited at school age.

There appears to be a gap in government services for school aged children

For families wishing to obtain a diagnosis or paediatricians seeking diagnostic clarification in the absence of mental health problems, referral directly to the Autism Spectrum Disorder Assessment Programme at Austin CAMHS, provides a diagnostic service by a multi disciplinary team in keeping with the NICE ( National Institute of Health and Care Excellence, UK 2011) clinical guidelines. These guidelines have been adopted as best practice by the Austin Mental Health Clinical Services Unit. This service however is only available to children aged 3- 12 yrs. There is a gap in access for families seeking diagnosis in older children without mental health difficulties . Although referrals for adolescents are occasionally accepted they are the exception and generally families must have the funds for private assessment. Children referred at school age are considered more complex and within the ASDAP programme, prior to assessment, are required to have obtained a current social communication assessment as well as cognitive assessment. Where the Education Dept is unable or unwilling to provide these assessments due to their own pressures of workload, families must also seek them privately adding to the financial burden on families.

The ASDAP programme operates one day per week and does not have the capacity to provide ongoing support, advice nor management strategies for struggling families. Whilst online parenting advice may be generically useful it does not address a parent’s dilemmas around the needs of an individual child. This task falls to early intervention services for children below 6 yrs however for families whose children are diagnosed at school age, services become more limited. Parents whose children are able to attend autism specific schools or special schools may be able to access some behavioural management information through their school. For parents of children with normal intelligence and ASD, there seems little in the way of individualised, specific ASD advice around parenting outside the private sector. Again requiring parents to pay and disadvantaging lower socio economic families.

Children with ASD and high intelligence seem to the most disadvantaged group with regard to diagnostic clarification and management. This is the group for whom late diagnosis ( ie over the age of 6) appears more anecdotally prevalent probably due to more subtle presentations and earlier misdiagnosis of behavioural disturbance. In the writer’s experience, many families for this group seem to struggle alone until a mental health problem arises bringing them into a CAMHS service where the diagnosis is made and ongoing management for ASD as well as mental illness is available.

Access to the health system

Facilities, staff training and awareness of the needs of those with ASD varies widely within the health system. Problems for the health system are more apparent for those patients who have a dual diagnosis of ASD and Intellectual Disability or for those with a more severe presentation of ASD.

The sensory needs of people with ASD are often overlooked or unmet in the urgency of presentation to an Emergency Dept. The bright lights, noise, frequent touch and fast paced information as well as a lack of understanding about ASD unfortunately may lead to increased distress and escalating fear and aggression. Emergency Departments should ideally be equipped with a space where sensory input can be minimised and staff have had some training and education around the needs of those with ASD.

Similar difficulties appear to exist for people with ASD needing to access an inpatient mental health facility. The needs of a person with ASD and significant intellectual disability experiencing mental illness, distress and aggression may be difficult to accommodate on a ward where the population, presentations and needs may be very different. In the writer's view, the primary diagnosis of ASD/ Intellectual Disability needs to be accommodated before the mental health needs can be addressed and this may best occur in a specialised facility with disability trained staff who have additional training in mental health. No such facility exists in Melbourne currently.

Doctors in busy outpatient departments generally need to make special arrangements for clients using public hospital outpatient clinics in order to avoid increased anxiety and the possibility of aggression and distress arising from waiting in large crowds. The likelihood of this occurring is dependent on both the facilities available and awareness of need by medical staff.

Integration of Govt Services

Government services are poorly integrated and appear to maintain strong boundaries around their identified clientele. This was reported by many clinicians and seems particularly evident between Disability Client Services and the Mental Health Sector where there is strong push back between the services for those with a dual diagnosis. It seems very difficult for families to access both services simultaneously despite meeting eligibility criteria for both. For families already engaged in mental health services it can be difficult to access additional services available only through Disability services.

Unmet demand in Disability Services

Support for families needing any form of respite ie emergency or planned, from government services is severely lacking. It is difficult for families to find such services when they are most needed and they often face long wait lists for services once found. The consequence of poor resourcing in this area is only increasing distress and the possibility of a breakdown in families due to chronic and high stress. Anecdotal feedback by the parent group is also that respite carers are not always well trained in understanding autism and there is poor oversight of the quality of services when they have been outsourced from a major provider.

Education Sector

The 2009 State Autism Plan articulates that one of its aims was to increase ASD expertise in order to offer options and support in both specialist and mainstream, government and non-government schools. This included a review of the Programme support criteria for integration funding for the provision of classroom aides.

Currently there are only 15 mainstream schools in Victoria designated as 'Autism friendly' by the Dept of Education and Early Childhood Development. Of these only 3 are secondary schools. Within the northern metropolitan region, only one school is available in Flemington making access to this school very difficult and unfeasible for many families with long distances to travel. For young people with ASD and normal intelligence, limited facilities within the education sector as well as a poor understanding of the needs of this population only serves to increase distress and contributes to escalating anxiety and mental health problems. Although schools have access to the Language Support Programme, the availability of this programme varies widely across networks and does not seem to be offered some areas. In the experience of the writer, mainstream schools as a general rule, have only a cursory understanding of ASD and would benefit from more education and support. The provision of support to academically bright ASD students in schools is

limited and these students are not eligible for integration funding within the Dept of Education as their normal intelligence excludes them. They risk not reaching their educational potential due to difficulties in being understood in mainstream schools and in schools having few resources to support or understand their needs.

NDIS
The impact of the NDIS is yet unknown and due to start 1.7.16 in the north-east region.
The NDIS appears to require entry for services for young children and people with ASD via a multi-disciplinary assessment in keeping with the NICE guidelines. There is a possibility that waiting lists for CAMHS ASD assessments may escalate however this is not known.

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