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Family and Community Development Committee

SUBMISSION TO

INQUIRY INTO SERVICE FOR PEOPLE WITH AUTISM SPECTRUM DISORDER

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BACKGROUND INFORMATION ABOUT ASD MENTAL HEALTH SERVICES, SERVICE DEVELOPMENT AND TRAINING IN VICTORIA THAT INFORMS THIS SUBMISSION

WHO ARE WE? MINDFUL, CENTRE FOR RESEARCH AND DEVELOPMENTAL HEALTH

Mindful Centre for Training and Research in Developmental Health is the state-wide unit responsible for the delivery of postgraduate courses, training programs, professional development and research programs in child and adolescent mental health.

Mindful is jointly auspiced by the University of Melbourne and Monash University and is funded by a Department of Health grant.

We have a teaching and research facility located in Flemington, Victoria and conduct postgraduate courses and professional development via distant education and video conference to rural participants.

Mindful received funding for four years from the Victorian Health Department's Autism State plan, to establish a training program of ongoing Professional Development Workshops in Assessment and Treatment of Autism Spectrum Disorder (ASD) and Neurodevelopmental Disorders. Over the last five years this program has trained over **1020 clinicians**. The program continues to expand and includes:

- ASD Fundamentals Assessment*
- Autism diagnostic observation Schedule 2 *
- Developmental, Dimensional and Diagnostic Interview, a ASD Computer Based Diagnostic Interview -3Di
- Psychoeducational Profile – Third Edition (PEP-3)
- Positive Behaviour Support strategies for Clinicians*
- Working with Young people with ASD and Comorbid Mental Health Disorders
- Working with ASD and Anxiety
- ASD and Adolescence

*These workshops are offer twice yearly to maintained a skill workforce

REGIONAL ASD COORDINATORS AND THE VICTORIAN AUTISM STATE PLAN 2009

Under the implementation of the Autism State Plan each Child & Adolescent Mental Health Service (CAMHS)/ Child & Youth Mental Health Service (CYMHS) and Orygen Youth Health were allocated ongoing funding for an ASD Coordinator* to coordinate the ASD assessment and diagnostic process, oversee the delivery of quality early intervention and ongoing clinical care within the mental health service and facilitate referral pathways to appropriate support services.



In addition to coordinating services and demonstrating leadership within the mental health service system regarding ASD, the local coordinators also link in with key service providers in their local areas such as paediatricians, disability services, early childhood services and student support services from the Department of Education and Early Childhood Development to assist with local coordination of ASD service delivery.

These coordinators provide a network of services for children and young people with ASD who have a complex presentation or are difficult to diagnose. Many present with additional mental health disorders such as anxiety and depression. In addition these children may also have experienced trauma, family breakdown, non-attendance at school; homelessness, criminal justice system, socio economic hardship and /or CALD Background. There is also an increase in the number of girls referred for ASD assessment, which has previously been a largely unrecognised cohort.

Through this ASD CAMHS/CYMHS network many of our most vulnerable and disadvantaged children and young people with suspected ASD have access diagnostic and treatment services.

*See Appendix 1 – List of current ASD coordinators.

ASD STATEWIDE COORDINATOR MENTAL HEALTH

Also as part of the implementation of the Autism State Plan time limited funding was provided for the establishment of a dedicated state wide ASD coordinator whose role was to support regional ASD coordinators, to develop practice guidelines, *A Guide to Identification, Diagnosis and Treatment of Autism Spectrum Disorders in Victorian Mental Health Services* (Kerry Bull & Sandra Radovini, April 2013) and establish a high quality ongoing training calendar to facilitate a CMYHS workforce skilled in ASD treatment and diagnosis.

The ASD Statewide coordinator regularly collects data, provided by regional coordinators, regarding regional waiting lists, regional issues and challenges to the provision of quality services, as well as local training needs. This role also provides mentoring and supervision to newly appointed ASD coordinators.

The hub and spoke model of a Statewide ASD coordinator and regional ASD coordinators has achieved the aims set out by the Autism State Plan to improve services and clinician skills within the mental health sector. It has been successful in providing training to Tertiary services (Tier 3 such as CAMHS/CYMHS) and Tier 2 service such as DHHS, Education Department Staff, Headspace, Work Rehabilitation Services, Early Intervention workers, Family Support workers, private practitioners, Paediatric Registrars and private Paediatricians, and others. Training numbers continue to increase each year, with 300 clinicians attending ASD training last year and, as previously stated, Mindful has trained over 1020 clinicians from various service sectors over the past five years in the field of ASD.

HOW IS ASD DIAGNOSED

There are a number of key guidelines on the assessment of ASD, international guidelines, such as the *National Institute for Health and Care Excellence* (2014) and local guidelines such as *Autism Victoria's Diagnostic Process for Children, Adolescents and Adults Referred for*



Assessment of Autism Spectrum Disorders (2010). These guidelines recommend the assessment of ASD is completed in collaboration by the following professions:

- Paediatrician or Child & Adolescent Psychiatrist
- Speech Pathologist
- Psychologist

Other professions such as occupational therapists, neuropsychologists, social workers and others may also be involved depending on the needs of the individual child and the context where the assessment occurs.

The agreed criteria for the diagnosis of ASD is defined within Diagnostic Statistical Manual of Mental Disorders (DSM-5) which is a mental health classification system. The criteria focus on the presence and or history of restricted and repetitive behaviours and interests, and significant social communication difficulties.

KEY ISSUES IDENTIFIED BY VICTORIAN METROPOLITAN ASD COORDINATORS

The major issues of concern to the Metropolitan ASD coordinators are:

- Access to quality services
- Lack of integration across government services
- Training and workforce issues
- Continuity of past positive initiatives for children, young people and families

Access to quality services

From waiting list data collected across the state from the ASD coordinators of the tertiary neurodevelopmental assessment teams there is a very clear inequity of access to services with significantly longer waiting lists in Western Region of metropolitan Melbourne and in rural areas. Of note, there are several rural areas with significant longer waiting lists than others.

In the eastern and southern areas of Melbourne waiting times have varied over the past few years from 1 month - 6 months, reflecting the accessibility of high numbers of public and private services in this region of Melbourne and the socio economic capacity of some families in these areas to access private services. This is compared with the Western metropolitan region of Melbourne where waiting lists are well over 12 months despite having several dedicated ASD assessment teams at RCH, Melton Health Service and Sunshine Hospital. This reflects a high need for western region clients to have access to publically funded clinics due to significant socio economic disadvantage and large numbers of CALD families requiring access to interpreters, not readily available in the private sector assessments. These issues are also evident in regional areas with high waiting lists such as Shepparton and Bendigo.

This inequity of services provision in metropolitan Melbourne has been mapped and presented in a submission to the 2014 Australian Senate's Community Affairs Reference Committee 'Inquiry into the Prevalence of different types of speech, language and communication disorders and speech pathology in Australia' submission 161, from Centre of Excellence in Child Language, Murdoch Research Institute. The location of public and private speech pathology and early intervention services are mapped against areas of language and cognitive skill



vulnerability. This map shows clearly the inequity of service distribution across Melbourne with very few services in Western metropolitan Melbourne and the very outer suburbs of Melbourne.

Young adults with ASD, discharged from mental health services also experience limited access to services. There is a scarcity of clinicians working with adult ADS clients in North Western and Western region of Melbourne where there are few options for young people over 18 to access low cost ASD assessment. Headspace is the major Tier 2 service for young people with mental health issues however, it does not have access to the multidisciplinary staff needed to provide ASD assessments.

Lack of integration across government services

ASD assessment and treatment should be a seamless process that can occur across government services to meet the needs of the individual child or young person who presents at a primary, secondary or tertiary agency. Currently there are local agencies such as community health centres and early intervention agencies whose policies prevent professionals working together across and within agencies to provide a comprehensive multidisciplinary assessment at the service of first contact. In some regional areas these policy barriers have been overcome and as a consequence children and their families receive more timely diagnosis. The following are some examples of a lack of service integration.

- In many regions of Melbourne there are community health centres employing a paediatrician and allied health that potentially could provide early diagnosis for many children with a clear or obvious presentation of ASD. However, they are currently thwarted by local policies.
- There are also barriers to young people with ASD, accessing Mental Health Community Support Services (formally PDRSS) that have in the in the past declined referrals for young people based on the fact that they have an ASD diagnosis
- Regional and metropolitan ASD coordinators report that access to Disability Services is limited and families report very limited provision of respite care. Families also have difficulty accessing case management support through Disability Services. This is also problematic for young people seen by Orygen Youth Mental Health Service

Addressing internal and inter- agency barriers to diagnosis and treatment of ASD would assist families by providing timely diagnosis and treatment, thus reducing stressors on families and reducing the likelihood of the child developing secondary problems due to a lack of appropriate diagnosis and understanding.

Training and workforce issues

Building a highly skilled workforce requires quality training and relative ease of access to training. It is our experience, as ASD coordinators, that capacity building relies on continuous funding streams to maintain an ASD skilled workforce. It has taken several years to build a training calendar that meets the needs of the tertiary mental health sector, while also meeting the training needs of many Tier 2 clinicians. At Mindful, the original funding allowed much of the training in the first few years to be offered free or at low cost which managed to reach the bulk of the CAMHS/CYMHS workforce. The training has now been further developed to address the needs of other agencies. Training across service systems needs to be available regularly to address workforce attrition and the ongoing sustainability of skills.



These training initiatives have made a huge difference to the availability of high quality, gold standard assessments within the CAMHS/CYMHS sector and enhanced the treatment offered to children and young people with ASD and other comorbid mental health disorders. It has also assisted training staff in a wide range of services, other than CAMHS/CYMHS in assessment and management of ASD.

KEY REGIONAL ISSUES IDENTIFIED BY VICTORIAN REGIONAL ASD COORDINATORS

ASD regional coordinators collaborate closely with local service agencies to provide comprehensive and high quality ASD assessment and treatment. Common issues across the rural areas which are likely to persist beyond the introduction of NDIS include:

- Lack of access to allied health disciplines, particularly speech pathology within regional CAMHS/CYMHS for diagnosis and treatment. Paediatric/child psychiatrist, psychologist and Speech Pathology assessments are regarded best practice for a diagnosis of ASD, (see NICE guidelines)
- Limited access to private or public services for ongoing care and treatment
- Few Paediatricians and Child & Adolescent Psychiatrists
- Maintenance of a skilled workforce.

Many regional ASD coordinators have come up with creative solutions in their local area to address some of these challenges. Here are some examples of these:

Lack of access to allied health, specifically Speech pathology

An assessment of language and social communication skills is a critical component of an ASD assessment. Therefore, the lack of access to speech pathology is a major problem for agencies attempting to provide diagnostic services without this essential component.

Some regional teams have formed partnerships with other local agencies or private

- North East CYMHS has formed a partnership with private speech pathologists for diagnostic purposes.
- Mildura CYMHS diagnostic team works in partnership with the allied health staff from the local community health centre and also with private paediatricians to ensure children receive a comprehensive assessment

However, despite these initiatives, the lack of available Speech Pathologists in rural area continues to significantly impact on the availability of thorough and timely assessment.

Inequity of access to services and professionals due to limited numbers of these professionals in regional areas.

With the introduction of NDIS, the lack of access to professionals will be more evident as families are likely to receiving funding for speech pathology, occupational therapy or psychology. There will not be sufficient local practitioners to meet this demand. There is an urgent need for more local public and private services. New graduates may be attracted to new positions created but will require access to mentoring and high quality supervision.



Perhaps incentives should be considered to encourage new graduates and experienced clinicians to work in regional areas. The use of technology to provide distance supervision and consultation services for regional staff should also be considered. This recommendation would require additional staff and funding to provide the level of support required.

Effective utilization of the skilled workforce in regional areas.

In many regional areas CAMHS/CYMHS staff have availed themselves of training offered through the ASD program at Mindful and in most regional areas waiting lists are as low as 6 months with only a few exceptions.

Sometimes local issues and lack of staffing can prevent staff utilizing their ASD assessment skills due to other service priorities. For example, in one regional CAMHS/CYMHS most of the staff are trained in a range of specific ASD assessments but due to the high demands on very small mental health teams in regional areas these skills are not always able to be utilized, due to other service priorities particularly crisis assessments.

Concerns of specific regions

GV CYMHS Shepparton & Seymour in particular has been experiencing high demand and long waiting lists of up to two years. Lack of a CAMHS/CYMHS employed speech pathologist is a major barrier to completing ASD assessments. Without the speech and language assessment completed by a speech pathologist, it is not possible to complete the ASD assessment for complex clients. To meet demand clinicians work collaboratively with private and public allied health and paediatricians. ASD/Neurodevelopmental assessments are also integrated within the general CAMHS/CYMHS assessment to attempt to meet demand.

Bendigo CYMHS have also experience high demand and long waiting lists. For these regions there are simply not enough resources to meet demand for complex or tertiary ASD assessments. Families in these regions frequently do not have the financial resources to seek private assessments, which would most often involve travel to Melbourne for private assessment.

WHAT HAS WORKED?

PAST INITIATIVES FOR CHILDREN AND YOUNG PEOPLE WITH ASD:

The ASD regional coordinators have collectively been part of many changes in the ASD service sector over the last six years. There have been many positive initiatives that have brought about improvement in the lives of children and young people with ASD. However funding for these initiatives has often been short term. Education has been one area where there has been a noticeable improvement in the past six years. In many schools' the capacity and confidence to manage and support children with ASD has advanced in response to several state and federal government initiatives.

There have been a variety of helpful programs introduced in Victoria over the past few years. This has included:



- Parent Education Programs such as ACT- NOW for preschool children and Positive Local cross agency networking groups " React"
- Case consultant practitioners.
- Waiting list reduction initiatives
- Behaviour Support for parents of children and young people 6-25yrs
- Supports for Schools- Regional Autism Coaches
- Specific funding for Training for CAMHS/CYMHS and other sectors

IMPACT OF NDIS

We are hopeful that NDIS will provide a better service for all children, young people and adults with ASD and other neurodevelopmental disorders. However currently it is clear that the existing services that are likely to provide the workforce for the implementation of NDIS are not sufficient in rural areas or in outer metropolitan Melbourne, partially the Western suburbs. These areas do not have adequate existing infrastructure and workforce to meet current demand, let alone the likely increased demand under NDIS.

Some rural regional areas are already noticing a decrease in service provision with state government agencies struggling to maintain and recruit staff in the lead up to the implementation of the NDIS.

We recommend:

- A focus on equity of access for all Victorians to Paediatricians, Child & Adolescent Psychiatrists and allied health staff, in rural Victorian and Western Metropolitan Melbourne.
- Addressing the lack of speech pathology in many rural regional areas.
- Addressing internal and inter agency policy barriers that prevent families from accessing early diagnosis and treatment in their local community agencies.
- A continued focus and investment on education of all clinicians working with ASD across infancy to adulthood including both public and private practitioners. This will ensure quality assessment and treatment of all people with ASD in Victoria.



REFERENCES

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National Institute for Health and Clinical Excellence, Autism in under 19s: recognition, referral and diagnosis. 2014

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Submission 161 Centre of Research Excellence in Child Language Murdoch Children's Research Institute. Map of therapy service distribution *Location of public and private speech pathologists in Victoria mapped against areas of language and cognitive skill vulnerability & AED2 data*, Page 10.