



**ST VINCENT'S
HEALTH AUSTRALIA**

UNDER THE STEWARDSHIP OF MARY AIKENHEAD MINISTRIES

St Vincent's Health Australia

Submission to the Select Committee on Autism

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The background features abstract, overlapping geometric shapes in various shades of blue, ranging from light sky blue to deep navy blue. The shapes are primarily triangles and quadrilaterals, creating a dynamic, layered effect. The top-left corner is dominated by a large, dark blue triangle pointing towards the center. Other shapes are scattered across the page, some pointing towards the bottom-right, creating a sense of movement and depth.

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1 INTRODUCTION

Autism Spectrum Disorder (ASD) is a lifelong neurodevelopmental disorder, of as yet unknown cause, characterised by persistent and pervasive social communication impairment, restricted repetitive patterns of speech, interests and behaviours, and unusual sensory processing¹. There is a large variation in how ASD presents in each person and each person may experience ASD in different ways. However, as a consequence, most autistic individuals experience significant challenges understanding the world around them, negotiating everyday living, and interacting with others. A significant proportion have complex needs and will require intensive intervention and long-term support². The focus of research, interventions and supports have however concentrated almost exclusively on children³. Services for adults with ASD are sparse and this group face significant difficulty accessing appropriate or adequate health care at all levels of the service system^{4 5}.

ASD is currently the largest primary disability category for the National Disability Insurance Scheme (NDIS). As at 31 December 2018, 29% of active participants with an approved plan had a primary disability of ASD, followed by intellectual disability, with 27%. Additionally, about 5% of participants had ASD as a secondary disability, with two-thirds of these having a primary intellectual disability. Compared to the group with disabilities other than ASD, average committed supports for participants with ASD are higher for ages 25 and over.⁶

This submission will provide information regarding the experiences of St Vincent's Health Australia services for people with neurodevelopmental disabilities (including ASD). The Terms of Reference addressed in this submission are outlined in section two.

1.1 ABOUT ST VINCENT'S HEALTH AUSTRALIA

St Vincent's Health Australia has been providing health care in Australia for more than 160 years, since our first hospital was established in Sydney in 1857 by the Sisters of Charity.

Today, St Vincent's Health Australia is the nation's largest not-for-profit health and aged care provider. We operate six public hospitals, 10 private hospitals and 20 aged care facilities in Queensland, New South Wales and Victoria. Along with three co-located research institutes – the Victor Chang Cardiac Research Institute, the Garvan Institute of Medical Research, and St Vincent's Institute of Medical Research – we work in close partnership with other research bodies, universities, and health care providers.

We are a clinical and education leader with a national and international reputation in medical research. Our areas of expertise include heart lung transplantation; bone marrow transplantation; cardiology; neurosurgery; cancer; clinical genomics; HIV medicine; palliative care; respiratory medicine; mental health; drug and alcohol services; aged psychiatry; homeless health; and prisoner health.

¹ American Psychiatric Association 2013. Diagnostic and statistical manual of mental disorders (5th ed.). Washington, DC

² Baxter, A. J., Brugha, T. S., Erskine, H. E., Scheurer, R. W., Vos, T., & Scott, J. G. (2015). The epidemiology and global burden of autism spectrum disorders. *Psychological medicine*, 45(3), 601

³ Howlin, P., & Magiati, I. (2017). Autism spectrum disorder: Outcomes in adulthood. *Current Opinion in Psychiatry*, 30(2), 69-76.

⁴ Victorian Parliament 2017. Inquiry into Services for People with Autism Spectrum Disorder - Final Report. Family and Community Development Committee. June 2017. Available at <https://www.parliament.vic.gov.au/fcdc/article/2588>.

⁵ Autism Awareness (2014) A national survey of autism parents and carers Summary Report <https://www.autismawareness.com.au/wp-content/uploads/2014/08/Autism2014-Survey-Summary-Report-for-AAA.pdf>

⁶ National Disability Insurance Agency. Outcomes for participants with ASD 30 June 2018.

St Vincent's Health Australia employs around 20,650 staff and operates more than 3,000 hospital beds and 2,400 residential aged care places. In our hospitals, we provide more than 1 million episodes of care for patients each year.

St Vincent's Health Australia provides compassionate healthcare to all people. Our Mission calls us to a special commitment to people from vulnerable and marginalised backgrounds.

1.2 ST VINCENT'S HOSPITAL MELBOURNE AND THE VICTORIAN DUAL DISABILITY SERVICE

The Victorian Dual Disability Service (VDDS), located at St Vincent's Hospital Melbourne, is a specialist state-wide mental health service for people with neurodevelopmental disabilities (including ASD) aged 16 years of age and above. The VDDS works with mental health services and the NDIS across the whole of Victoria to provide assessment and consultation in relation to developmental disability mental health. The VDDS also provides education and training for mental health clinicians and disability sector workers. The VDDS vision is that people with developmental disabilities should have access to the best possible mental health care and the service works with consumers, families, carers, and service providers to help individuals achieve the highest attainable standard of mental health and wellbeing.

A review of individuals referred to the VDDS over a four year period 2015- 2019 found that autistic people comprised 23% of those referred to the service and that this population had significant multiple complex needs – including high rates of concurrent mental and behavioural disorders – but that they experienced difficulty accessing appropriate mental health services.

2 TERMS OF REFERENCE

This submission will specifically address Terms of Reference (a), (b), (e), (f), (h) and (j).

a) Current approaches and barriers to consistent, timely and best practice autism diagnosis.

There are considerable barriers to consistent, timely, affordable and best-practice autism diagnosis for those over 18 years of age. These barriers include:

- Difficulty accessing ASD assessment because there are few available services. Resources for adult assessment are extremely limited, and publicly funded autism assessment and diagnostic services are scarce.
- Prohibitive costs associated with the very limited private services that are available.
- Extremely limited assessment options in regional and rural settings, which results in people needing to travel long distances and in some instances transporting an individual who has significant behaviours of concern.
- A lack of clear pathways to obtain assessment with no service specifically responsible for undertaking assessments, especially for those who do not have a concurrent intellectual disability.
- Limited knowledge of ASD by front line services and limited awareness about how to access assessment services.
- Lack of service cohesion and poor inter-agency communication and collaboration which complicates the collection of developmental information necessary to make a diagnosis in adults.

Recommendations:

- Development of specialist autism services that can provide timely consultation and liaison to all health and NDIS service providers to provide assessment and diagnosis of ASD across the lifespan. In addition, this service would provide assessment, diagnosis, treatment and management of ASD and associated mental health needs where their needs cannot be met by existing mental health services. Services will also need to have sufficient funding and resources to undertake research and will act as centres of excellence. Increased access for adults to affordable autism assessment and diagnosis and development of easily accessible referral pathways.
- Amendment to the Medicare Benefits Schedule to allow for rebated ASD assessments for adults by Psychiatrists, Nurse Practitioners and Allied Health Professionals.

b) The prevalence of autism in Australia.

In recent years there has been a marked increase in the number of people identified with ASD, in 2018 there were 205,200 Australians with autism, a 25.1% increase from the 164,000 with the condition in 2015⁷. ASD is now estimated to occur in approximately 2.8% of children⁸. Data is lacking on the rate of ASD in adults but in one of the few published studies, a large scale investigation in the UK found that 1.1% of the adult population had ASD and that many for of these individuals had not been previously diagnosed⁹. The true prevalence of ASD in Australian adults is likely to be higher given the large numbers of autistic adults who remain undiagnosed.

The prevalence of ASD among adult consumers of mental health services has not been widely studied but the limited research currently available suggest it has increased among psychiatric inpatients¹⁰ and people presenting to emergency departments for mental health issues¹¹.

Recommendations:

- Specific attention to mental health across the lifespan in the development of a National Autism Plan.
- Development of a strategy that includes data collection and research into the prevalence of ASD in adults and older adults, and also the prevalence, nature, and impact of co-morbid mental health issues.
- Research into the number of autistic people presenting to mental health services and outcomes.

e) The demand for, and adequacy of, Commonwealth, state and local government services to meet the needs of autistic people at all life stages.

People with autism experience very poor physical and mental health compared to the general

⁷ ABS, 2019, 4430.0 - Disability, Ageing and Carers, Australia: Summary of Findings, 2018. <https://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/4430.0Main%20Features102018?opendocument&tabname=Summary&prodno=4430.0&issue=2018&num=&view>

⁸ ABS, 2017, 4430.0 - Disability, Ageing and Carers, Australia: Summary of Findings, 2015. <http://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/4430.0Main%20Features752015>

⁹ Brugha, T. S., McManus, S., Bankart, J., Scott, F., Purdon, S., Smith, J., ... & Meltzer, H. (2011). Epidemiology of autism spectrum disorders in adults in the community in England. *Archives of general psychiatry*, 68(5), 459-465.

¹⁰ Tromans, S., Chester, V., Kiani, R., Alexander, R., & Brugha, T. (2018). The prevalence of autism spectrum disorders in adult psychiatric inpatients: a systematic review. *Clinical practice and epidemiology in mental health: CP & EMH*, 14, 177.

¹¹ Vohra, R., Madhavan, S., & Sambamoorthi, U. (2016). Emergency department use among adults with autism spectrum disorders (ASD). *Journal of Autism and Developmental Disorders*, 46(4), 1441-1454.

population. Studies show very high rates of the whole range of psychiatric disorders among autistic individuals across all areas of the autism spectrum with between 50-70% experiencing co-existing mental disorders^{12 13 14}. The presence of co-occurring mental disorders is associated with lower quality of life, greater demands for professional help and emergency services, poorer prognosis, major interference with everyday life, and very poor outcomes¹⁵. ASD is one of the neurodevelopmental disorders that includes Intellectual Disability (ID) and a significant proportion (approximately 50%) of people with ASD will also have ID. High rates of psychiatric co-morbidity are widely acknowledged amongst the ID population and those with concurrent ASD and ID would therefore be expected to experience markedly increased risk of mental health problems.

Furthermore, poor physical health, socio-economic status and lack of social supports experienced by this population exacerbate mental ill health. Anxiety and depression is particularly common and autistic individuals experience high rates of suicidal ideation¹⁶. Recent studies also show higher rates of psychotic disorders than found in the general population^{17 18} but analysis of referrals to the VDDS shows that mental health services experience considerable difficulty differentiating between these disorders. Difficulties with communication, atypical presentation of mental health problems, challenges with assessment and diagnosis, and the need for a modified approach to treatment and management means that significant reasonable adjustments to practice, a high level of psychiatric expertise, and a good understanding of autism by clinicians is needed to provide this vulnerable population with the same standard of health care as afforded to the general population¹⁹. ASD is also a major source of stress and mental ill health for family and carers, for whom supports rapidly diminish when the autistic individual reaches adulthood²⁰.

Recommendation:

- Information is currently fragmented and there needs to be an easily accessible central point for people to obtain information specifically in relation to autism and mental health, including where to access services and supports and which practitioners specialise in this area.

f) The interaction between services provided by the Commonwealth, state and local governments, including:

i). health and mental health

Despite the high rates of mental illness in autistic people, individuals and families consistently report difficulty accessing mental health services across the entire continuum of care, including primary health, mainstream mental health, emergency and crisis support, and specialist services^{21 22}. This is

¹² Lever, A. G., & Geurts, H. M. (2016). Psychiatric co-occurring symptoms and disorders in young, middle-aged, and older adults with autism spectrum disorder. *Journal of autism and developmental disorders*, 46(6), 1916-1930

¹³ Australian Advisory Board on Autism Spectrum Disorders 2012, *The Interface between Autism Spectrum Disorders and Mental Health: The Ways Forward*. Discussion paper, December 2012

¹⁴ Hollocks, M. J., Lerh, J. W., Magiati, I., Meiser-Stedman, R., & Brugha, T. S. (2019). Anxiety and depression in adults with autism spectrum disorder: a systematic review and meta-analysis. *Psychological medicine*, 49(4), 559-572.

¹⁵ Howlin, P., & Magiati, I. (2017). Autism spectrum disorder: Outcomes in adulthood. *Current Opinion in Psychiatry*, 30(2), 69-76

¹⁶ Hollocks, M. J., Lerh, J. W., Magiati, I., Meiser-Stedman, R., & Brugha, T. S. (2019). Anxiety and depression in adults with autism spectrum disorder: a systematic review and meta-analysis. *Psychological medicine*, 49(4), 559-572

¹⁷ Cvejic, R. C., Arnold, S. R., Foley, K. R., & Trollor, J. N. (2018). Neuropsychiatric profile and psychotropic medication use in adults with autism spectrum disorder: results from the Australian longitudinal study of adults with autism. *BJPsych open*, 4(6), 461-466.

¹⁸ Esbensen, A. J., Greenberg, J. S., Seltzer, M. M., & Aman, M. G. (2009). A longitudinal investigation of psychotropic and non-psychotropic medication use among adolescents and adults with autism spectrum disorders. *Journal of autism and developmental disorders*, 39(9), 1339-1349

¹⁹ Ghaziuddin, M. (2005). *Mental health aspects of autism and Asperger syndrome*. Jessica Kingsley Publishers

²⁰ Ghaziuddin, M. (2005). *Mental health aspects of autism and Asperger syndrome*. Jessica Kingsley Publishers

²¹ Crane, L., Adams, F., Harper, G., Welch, J., & Pellicano, E. (2019). 'Something needs to change': mental health experiences of young autistic adults in England. *Autism*, 23(2), 477-493.

²² Camm-Crosbie, L., Bradley, L., Shaw, R., Baron-Cohen, S., & Cassidy, S. (2019). 'People like me don't get support': Autistic adults' experiences of support and treatment for mental health difficulties, self-injury and suicidality. *Autism*, 23(6), 1431-1441.

highlighted by a study in Australia of autistic adults by Aspect in 2013 that found only half were receiving the help they needed for mental health conditions²³. In the majority of instances where mental illness and developmental disability co-exist, they often cannot be differentiated and require a coordinated collaborative approach between services. However, limited collaboration between the National Disability Insurance Scheme (NDIS), public mental health services, primary health, and private providers, results in individuals receiving inadequate supports or experiencing considerable delays in service provision. This situation is compounded by the limited and fragmented specialist services that are available.

It is widely acknowledged that many autistic people have sensory sensitivity and can find sensory stimuli aversive. For example, noise, bright lights, lots of movement, being touched, and different smells can be incredibly aversive and precipitate severe distress and behavioural meltdowns. Social communication impairments can result in the person experiencing difficulty coping with new environments, changes in routine, and not knowing exactly what to expect. Difficulties with planning, sequencing, understanding complex instructions and processing information are also reported by many individuals. Health environments and procedures are invariably aversive with limited adaptation or reasonable adjustment of the sensory or social settings and limited attention to modifying communication. Consequently this can cause an autistic person considerable distress and result in disturbed behaviour because the individual is overwhelmed. Strategies to support autistic people often involve communicating clearly, providing structure, and a low arousal environment.

Recommendations:

- A review of MBS-rebated mental health sessions as the current settings do not adequately reflect the mental health needs of autistic people who frequently need more frequent sessions over longer periods.
- Development of clinical pathways and clinical practice guidelines for mental health assessment and intervention that include guidance on improved coordination between different healthcare services and the NDIS.
- Reasonable adjustments should be a mandated requirement for health services, along with advice and information provided to health services. A specialist autism team should have a key role in the advice and training for other health and social care services and consultation on provision of reasonable adjustments.
- Development of consistent health information in accessible formats for autistic adults and their carers.

h) The adequacy and efficacy of the National Disability Insurance Scheme (NDIS) for autistic people

iii). the ability of the NDIS to support autistic people with complex needs, including those transitioning from prison settings.

The VDDS has encountered a particular problem for a number of autistic individuals with highly complex needs, often including severe aggression or self-injury, where they are not identified as eligible for a mainstream mental health service as they do not meet the diagnostic criteria.

²³ Australia, A. S. (2013). We belong: The experiences, aspirations and needs of adults with Asperger's disorder and high functioning autism. Sydney: Autism Spectrum Australia.

St Vincent's Hospital Melbourne sees a small but significant number of autistic individuals who cannot remain in their accommodation because of severe behaviours of concern (that may or may not be related to mental health problems) and multiple complex needs. They need robust specialist disability accommodation which is in short supply. In a number of instances these people are placed in hotel rooms with NDIS-funded staff support, usually at a 2:1 ratio, 24 hours a day, 7 days a week. In many instances these carers have limited training, supervision or support in either ASD or mental health.

Sometimes these individuals have been placed in mental health units or medical wards where they have remained for lengthy periods as they have nowhere else to go and have been cared for by clinicians who frequently have little or no understanding of ASD.

In many instances, adult mental health clinicians and direct carers lack adequate understanding of autism leading to ASD being missed or misinterpreted and there are significant rates of misdiagnosis leading to inadequate or inappropriate treatment. People with ASD are frequently reported to demonstrate behaviours of concern such as aggression, property destruction, disruptive, and self-injurious behaviour. As a consequence autistic individuals are at increased risk of being subject to restrictive interventions including high rates of off-label psychotropic medication²⁴ that is vastly higher than the reported rates of treatable mental illness. Conversely people with ASD may also not receive the appropriate treatment that they require for their mental health problems as every problem is viewed entirely in the context of their disability, resulting in deterioration of their mental health^{25 26}.

Recommendations:

- Development of capacity and skills in the health workforce by including content on ASD in undergraduate training courses and increasing education on ASD and mental health for current clinicians. Introducing mandatory training in ASD mental health for all front line mental health staff.
- Increasing mandatory education and training on mental health and ASD for all NDIS-funded support staff who are supporting people with ASD.
- Development of state-wide services for ASD mental health in each state or territory which can provide specialised assessment, treatment planning, and interdisciplinary interventions for those with multiple complex needs, or in situations where there is controversy over diagnosis or management. This would include establishment of inpatient resources and longer term accommodation and include a national strategy to examine and address the use of restrictive interventions across all service systems.
- Development of appropriate mental health supports for families and carers of autistic individuals.
- Development of specific ASD consultation liaison (CL) services for general hospitals. These services would provide assistance to prepare autistic patients and hospitals for the admission,

²⁴ Howes, O. D., Rogdaki, M., Findon, J. L., Wichers, R. H., Charman, T., King, B. H., ... & Povey, C. (2018). Autism spectrum disorder: Consensus guidelines on assessment, treatment and research from the British Association for Psychopharmacology. *Journal of Psychopharmacology*, 32(1), 3-29.

²⁵ Buck, T. R., Viskochil, J., Farley, M., Coon, H., McMahon, W. M., Morgan, J., & Bilder, D. A. (2014). Psychiatric comorbidity and medication use in adults with autism spectrum disorder. *Journal of autism and developmental disorders*, 44(12), 3063-3071.

²⁶ Fusar-Poli, L., Brondino, N., Rocchetti, M., Petrosino, B., Arillotta, D., Damiani, S., ... & Politi, P. (2019). Prevalence and predictors of psychotropic medication use in adolescents and adults with autism spectrum disorder in Italy: A cross-sectional study. *Psychiatry research*, 276, 203-209.

assist with reasonable adjustments, provide training and education on ASD and related mental health or behavioural issues, and provide expert input to prevent and minimise problems.

j) The adequacy of funding for research into autism

There is a lack of research on ASD in the adult population in general.

High rates of psychotropic medication are prescribed for autistic individuals despite the lack of research on safety or effectiveness in the adult population^{27 28 29}.

Recommendations:

- Establish a national forum for mental health and autism researchers, practitioners and consumer representatives to identify research priorities, capacity building requirements and opportunities for service collaboration.
- Increased funding for research into autism in adults including prevalence, prevalence of mental health problems, assessment, diagnosis, treatment, and service provision.

3 SUMMARY OF RECOMMENDATIONS

There are common issues experienced by people across the autism spectrum but the needs of people with significant cognitive impairments may be very different and require a different mental health response in comparison to those in the higher range of cognitive functioning. A range of service options will therefore be required in a stepped model that accounts for the varying impact of ASD and ID.

Recommendations, as included in the above sections, are set out below:

TERMS OF REFERENCE	RECOMMENDATIONS
(a) Current approaches and barriers to consistent, timely and best practice autism diagnosis	Development of specialist autism services that can provide timely consultation and liaison to all health and NDIS service providers to provide assessment and diagnosis of ASD across the lifespan. In addition this service would provide assessment, diagnosis, treatment and management of ASD and associated mental health needs where their needs cannot be met by existing mental health services. Services will also need to have sufficient funding and resources to undertake research and will act as centres of excellence. Increased access for adults to affordable autism assessment and diagnosis and development of easily accessible referral pathways.

²⁷ Esbensen, A. J., Greenberg, J. S., Seltzer, M. M., & Aman, M. G. (2009). A longitudinal investigation of psychotropic and non-psychotropic medication use among adolescents and adults with autism spectrum disorders. *Journal of autism and developmental disorders*, 39(9), 1339-1349.

²⁸ Jobski, K., Höfer, J., Hoffmann, F., & Bachmann, C. (2017). Use of psychotropic drugs in patients with autism spectrum disorders: a systematic review. *Acta Psychiatrica Scandinavica*, 135(1), 8-28.

²⁹ Jesner OS, Aref-Adib M, Coren E. Risperidone for autism spectrum disorder. *Cochrane Database of Systematic Reviews* 2007, Issue 1. Art. No.: CD005040. DOI:

	Amendment to the Medicare Benefits Schedule to allow for rebated ASD assessments for adults by Psychiatrists, Nurse Practitioners and Allied Health Professionals who have appropriate training in conducting ASD assessment for adults.
(b) The prevalence of autism in Australia.	Specific attention to mental health across the lifespan in the development of a National Autism Plan.
	Development of a strategy that includes data collection and research into the prevalence of ASD in adults and older adults, and also the prevalence, nature and impact of comorbid mental health issues.
	Research into the number of autistic people presenting to mental health services and outcomes.
(e) the demand for and adequacy of Commonwealth, state and local government services to meet the needs of autistic people at all life stages.	Information is currently fragmented and there needs to be an easily accessible central point for people to obtain information specifically in relation to autism and mental health, including where to access services and supports and which practitioners specialise in this area.
(f) the interaction between services provided by the Commonwealth, state and local governments, including: i. health and mental health	A review of MBS-rebated mental health sessions as the current settings do not adequately reflect the mental health needs of autistic people who frequently need more frequent sessions over longer periods.
	Development of clinical pathways and clinical practice guidelines for mental health assessment and intervention that include guidance on improved coordination between different healthcare services and the NDIS.
	Reasonable adjustments should be a mandated requirement for health services, along with advice and information provided to health services. A specialist autism team should have a key role in the advice and training for other health and social care services and consultation on provision of reasonable adjustments.
	Development of consistent health information in accessible formats for autistic adults and their carers.
(h) the adequacy and efficacy of the National Disability Insurance Scheme (NDIS) for autistic people iii. the ability of the NDIS to support autistic people with complex needs, including those transitioning from prison settings,	Development of capacity and skills in the health workforce by including content on ASD in undergraduate training courses and increasing education on ASD and mental health for current clinicians. Introducing mandatory training in ASD mental health for all front line mental health staff.

	Increasing mandatory education and training on mental health and ASD for all NDIS-funded support staff who are supporting people with ASD.
	Development of state-wide services for ASD mental health in each state or territory which can provide specialised assessment, treatment planning and interdisciplinary interventions for those with multiple complex needs, or in situations where there is controversy over diagnosis or management. This would include establishment of inpatient resources and longer term accommodation and include a national strategy to examine and address the use of restrictive interventions across all service systems.
	Development of appropriate mental health supports for families and carers of autistic individuals.
	Development of specific ASD consultation liaison (CL) services for general hospitals. These services would provide assistance to prepare autistic patients and hospitals for the admission, assist with reasonable adjustments, provide training and education on ASD and related mental health or behavioural issues and provide expert input to prevent and minimise problems.
(j) the adequacy of funding for research into autism	Establish a national forum for mental health and autism researchers, practitioners and consumer representatives to identify research priorities, capacity building requirements and opportunities for service collaboration.
	Increased funding for research into autism in adults including prevalence, prevalence of mental health problems, assessment, diagnosis, treatment and service provision.

4 CONCLUSION

People with Autism Spectrum Disorders are more likely to experience mental ill health than the general population but frequently struggle to access appropriate mental health care. Autism is a lifelong disorder and there are more adults with ASD although services for autistic adults are relatively scarce and underdeveloped. Access to appropriate mental health services is complicated by a range of factors not least of which is the lack of understanding of autism by health professionals.

St Vincent's Health Australia thank the Senate for this opportunity for input into this important issue. In this submission we have highlighted a number of issues and potential solutions. Should you wish to discuss the content of this submission please do not hesitate to contact us.

The following clinicians were involved in the development of this submission:

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