The Royal Australian & New Zealand College of Psychiatrists

Your Health in Mind

Department of Social Services

National Autism Strategy

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Improve the mental health of communities

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About the Royal Australian and New Zealand College of Psychiatrists

The Royal Australian and New Zealand College of Psychiatrists (RANZCP) is responsible for training, educating and representing psychiatrists in Australia and New Zealand. The RANZCP has more than 8000 members, including around 5800 qualified psychiatrists. The recommendations contained within this submission are based on consultation with RANZCP Committees, including the Faculty of Adult Psychiatry, Faculty of Child and Adolescent Psychiatry, Section of Youth Mental Health, Section of Child and Adolescent Forensic Psychiatry, Section of Psychiatry of Intellectual and Developmental Disabilities and the ADHD Network.

RANZCP Committees are made up of psychiatrists and community members with lived experience, and the RANZCP is well positioned to advise on this issue due to the breadth of academic, clinical, and service delivery expertise it represents.

Key recommendations:

The RANZCP welcomes the development of the National Autism Strategy (the Strategy) as a cohesive national approach to meet the needs of autistic people, and urges the Government to:

- include the voices of autistic people at all stages of the Strategy's development and implementation to support a more inclusive approach to policy development and service design.
- ensure the Strategy is supported by adequate funding to ensure appropriate implementation.

The RANZCP recommends that the Strategy:

- Identify and recommend solutions to reduce barriers for autistic people accessing services, including through adequate funding of the psychiatry workforce.
- Set out a clear implementation plan and evaluation framework for the Strategy.
- Address social inclusion by:
    - Incorporating autistic people into classrooms and other neurotypical learning environments.
    - Ensuring the Strategy embeds cultural identity and cultural safety into the diagnoses, care and treatment models for autistic people, particularly for Aboriginal and Torres Strait Islander peoples who are autistic.
- Address issues of economic inclusion faced by autistic people by:
    - Reduce the financial burden for seeking mental healthcare services, in particular diagnosis from psychiatrists.
    - Reforming the Disability Employment Services system and expanding autism specific employment programs.
- Increase training relating to autism for mainstream service clinicians, including adult presentations.
- Increase funding for research and data on the health needs of autistic people, to inform interventions and improve health outcomes.

Introduction

The RANZCP is grateful for the opportunity to contribute to the Strategy. As the peak body representing psychiatrists in Australia and New Zealand, the RANZCP represents members practicing in both the public and private health systems, as well as those in clinical and academic research. The RANZCP agrees that the purpose of the strategy should be reducing the burden on the Autistic community of retelling their stories, and to build on the available evidence while identifying gaps. The RANZCP has previously

highlighted the significant challenges and unmet mental health needs for autistic people in our Position Statement 110: Autism: Addressing the mental health needs of Autistic people.

Language

Individual preferences vary regarding the use of 'autistic person/people' and a 'person/people with autism'. This document will use 'Identity first' language to refer to autistic people as it is preferred.[1]

The need for a National Autism Strategy

The RANZCP welcomes the development of a National Autism Strategy to provide a coordinated approach across government and services to better serve autistic people and their families. As set out in our Position Statement, the RANZCP advocates for a cohesive national policy and systemic approach including the voices of autistic people.

Autistic people should be able to access all necessary supports to live a fulfilling and healthy life. When accessing support, autistic people have the right to access appropriate and respectful services across all sectors which are reflective and adaptive to each person's needs.

Systemic barriers must be removed to improve outcomes for autistic people.[2, 3] Over the past 12 months, 51% of autistic people aged 14 years and over reported facing barriers to access support.[4] Support structures are needed to regulate system performance issues to highlight barriers to equitable access.[5, 6] The Senate Select Committee on Autism identified the following drivers for poor outcomes for autistic people: poor understanding of autism among service provider, workforce constraints, delays in diagnosis and early intervention, complex service environment and services are not designed for autistic people.[7]

What does the National Autism Strategy need to achieve?

The Strategy needs to enact systemic change to support autistic Australians and their families. The RANZCP commends the Department for recognising the need for a strategy that focuses on social inclusion, economic inclusion, diagnosis, services and inclusion, and a national roadmap. The Strategy should consider the needs of autistic people within all relevant health, mental health and disability frameworks, and support the establishment of integrated, multidisciplinary approaches between sectors.

The Strategy must also be supported by adequate funding to ensure appropriate and thorough implementation and evaluation.

Reducing barriers in accessing services

Autistic people face systemic gaps in care which lead to illnesses not being diagnosed or treated.[9] To reduce barriers in accessing healthcare services faced by autistic people, the mental health workforce must be better resourced and supported.

Diagnosis of autism requires assessment by a psychiatrist or a psychologist.[8] Psychiatrists are important to the diagnostic pathway for autism and comorbid disorders and use their appropriate clinical and professional knowledge and diagnostic tools (DSM-V, ICD, etc.) to determine diagnosis. To obtain a diagnosis of autism from a psychiatrist, a client must undergo psychiatric assessment which may also diagnose comorbid disorders (such as Intellectual Disability, anxiety or ADHD).[8] Psychiatrists play an important leadership role in the diagnosis and treatment of autism.

The Productivity Commission Report, the National Skills Commission's Skills Priority List and the National Mental Health Workforce Strategy have identified a national shortage of psychiatrists. Without an adequate number of clinicians to meet the needs of the community, patients can be left under treated or without access to services entirely. This need is compounded by the increasing prevalence of autism.[9] As autism

diagnosis occurs predominantly in childhood, there is a particular need for greater funding for child and adolescent psychiatry.[10] Patients having greater access to affordable services is a key priority for the RANZCP. Raising demands on the existing mental health workforce also contributes to burnout, high rates of leave and staff exiting the workforce.

Social Inclusion

Autistic people experience higher rates of social isolation, which compounds with stigma and discrimination to act as a barrier to equitable mental healthcare access.[12, 13, 14] These effects can compound when autistic people belong to other stigmatised groups that face discrimination.[14, 15, 16]

Systemic social isolation can start in the classroom, as autistic children require more support and practice to navigate social situations.[16] Since autistic children experience more disruptions to school participation, they receive less total time developing the skills with their neurotypical peers. Autistic children that better mask their deficits may be underdiagnosed or diagnosed later in life.[18]

There is an increased rate of interaction with the justice system for autistic people, especially when there is a comorbid psychiatric diagnosis,[19, 20, 21] which compounds social isolation experienced by autistic people. Interaction with the justice system occurs in victim, offender and witness roles. autistic children are more likely to be victims of physical, emotional, and sexual abuse compared to neurotypical children.[22] The lack of a systematic identification of people with disability enables violence, abuse, neglect, and exploitation at all levels of the justice system.[23]

Gender differences in autism diagnosis are widely reported to be around 4:1 (male to female).[9] Recent data suggests this ratio is decreasing, with more females in Australia being diagnosed with autism.[24] The DSM-V noted the communication and social skill deficits autistic females may be more subtle.[17] Despite the subtlety, autistic females still require timely diagnosis and treatment to reduce their social isolation. Considering reported changes in gender differences, more research and training in identifying the manifestation of autism in females is required.[25]

To address social inclusion, the Strategy needs to ensure that autistic children are accommodated for in neurotypical classrooms, where there are no comorbidities of intellectual disability. This is supported by evidence that shows autistic people with typical peers show greater social responsiveness, stronger language reception skills, and more complex coordinated play.[23] These greater social skills aid development and social inclusion.

Autistic people may experience stigma and discrimination in a compounded way where they belong to other population groups which also experience stigma and discrimination.[3] For example, Aboriginal and Torres Strait Islander peoples who have autism have specific cultural identities and needs that require consideration when developing optimal care and support.[1] The Strategy should facilitate and embed cultural identity needs and cultural safety within the systems and supports it develops and effects.

Economic Inclusion

Autism exists among other developmental disabilities, which affect the physical, psychological, psychosocial and or intellectual development of a person throughout development. Significant associations and interactions occur between Autistic people and other measures of disadvantage.[26, 27] People with developmental or learning disability are at the highest risk of being disadvantaged in other way such as low participation in education, employment, and low income. Other disadvantages include locational disadvantage, poor socioeconomic outcomes, and poorer academic outcomes.[28] autistic people report having significantly lower annual income than the Australian mean annual income.[29] Due to lack of public sector capacity, many clients seek private mental health services, which is a significant financial burden for autistic people. The RANZCP advocates for the financial support of autistic people seeking diagnoses and

support by increasing the MBS rebate for psychiatry services to 100% of the schedule fee from the current 85%.

The cost of seeking private sector psychiatry and the availability of mental health services can result in delays in diagnosis. Delays increase the economic burden for autistic people, lead to poorer life outcomes, increase familial lost cost for informal carers and increase barriers to services.[31, 32] Employment outcome studies worldwide report lower rates of employment for autistic people.[32] In Australia the workforce participation rate is 41% for autistic people, compared to 83% for adults without a disability. Autistic people are more likely to be underemployed (29% compared to 8% of the Australian workforce), and underutilised (51% compared to 14% of the Australian workforce.[34]

The Strategy should address how infrastructure to support the autistic people throughout their lives will be established. Supporting employment will increase life outcomes for autistic people, as well as increase taxable earnings for autistic people and their families/informal carers.[36] The Disability Employment Services system should also be reformed to improve recruitment and expand autism-specific employment programs.

Diagnosis, Services and Supports

There remains a lack of understanding of autism and missed or misinterpreted diagnosis leads to inadequate or inappropriate treatment.[2, 3, 37] Undiagnosed adults may be treated for mental health conditions without recognition of their primary condition.[37] Early diagnosis and intervention must occur to allow autistic children to be provided with the social and educational supports to enable them to achieve their best potential. Early intervention has also been estimated to result in significant economic benefits.[36]

An improved understanding of autism in clinicians working in mainstream services would improve experiences and outcomes for people who are or may be autistic, particularly as referrals via mainstream services are a common pathway to adult diagnosis.[38, 39] Physical and mental health comorbid diagnoses are more common in autistic people.[3, 5, 7] The social isolation factors mentioned above are risk factors for comorbid mental health conditions such as depression.[11] Both intellectual disability and autism are associated with high rates of co-morbid medical and mental disorders, yet many have difficulty in accessing services due to a failure to consider their specific needs.[41] Autistic people with intellectual disability have been found to experience compounding disadvantage in health outcomes and service access.[18, 39, 40] The Strategy should clarify how support can be scaled to meet the more complex needs of autistic people with comorbid intellectual disability.

Funding for research and data collection

There is a lack of research on understanding the health needs of autistic people.[2, 11, 19] Due to the complexity of autism and its comorbidities, more research and data on health outcomes of autistic people are needed.[9] More research is also needed to support those diagnosed in adulthood, and to support recognition and diagnosis for people who are female and people who are linguistically diverse.[27, 42]

Summary

The RANZCP looks forward to providing further expert advice and feedback on the development of the National Autism Strategy. To discuss any of the comments raised in this submission, please contact Nicola Wright, Executive Manager, Policy, Practice, and Research Department via Nicola.wright@ranzcp.org or on (03) 0236 9103.

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