

Submission to the National Autism Strategy

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This submission is related to the overarching key discussion question: ***What can be done to better support Autistic people from different population groups – Autistic women and girls***

Autistic girls, women and gender diverse* people experience more physical and mental health challenges, have additional needs related to sexual and reproductive health and are at increased risk of sexual violence. However, there is a lack of specific research that addresses these critical areas of need. In addition, the research agenda has predominantly been set by researchers rather than the Autistic community. It is important to develop research priorities with Autistic girls, women and gender diverse people to provide research that is meaningful for their lives.

Co-produced research agenda for Autistic girls, women and gender diverse people in Australia

In 2022, we developed a co-produced research agenda for Autistic girls, women and gender diverse people in Australia. The project was led by a team of Autistic women and non-binary people. We conducted qualitative interviews with 47 Autistic girls, women and gender diverse people aged 7 and above. These interviews guided the development of a draft research agenda, which was finalised following additional feedback via an online survey completed by 411 Autistic girls, women and gender diverse people living in Australia. Research priorities were developed separately for young people and adults, to ensure that their differing needs were recognised.

This important and relevant research can critically inform the development of the National Autism Strategy. The priority areas we identified map onto key areas highlighted within the strategy, including health and mental health care, education, employment, social inclusion, and diagnosis, services and support. It also addresses the overarching key discussion question related to how to better support Autistic women and girls, and additionally considers the needs and experiences of gender diverse Autistic people.

Six key research areas were identified by Autistic girls and gender diverse young people

1. Better understanding and support at school

“The fact that I can be in like a school system where I don't receive the support I need because I'm not visibly struggling. I think there needs to be more awareness spread of how autism looks and that it's not a little mould that someone can fit into”

The first priority area outlines the need for an increased understanding of the learning experiences of Autistic girls and gender diverse young people, including the challenges of being in an environment that often is not responsive, accepting or accommodating to their diverse learning needs. It is also imperative for teaching staff, leadership and education policy makers to increase their understanding of autism and the support and accommodation needs of their Autistic students.

* this includes cisgender women and girls, transgender, non-binary, and gender diverse people, and anyone who was socialised, or identifies as a woman or girl

2. Understanding our experiences, strengths and challenges

“I was a bit confused about all this stuff because I didn’t really see representation of an Autistic person that looked or acted like me, a girl, a teenager, all of these things”

The second priority area highlights the necessity for greater understanding of autism in girls and gender diverse young people, including significantly more insight into their experiences of puberty, mental and physical health, and their sensory and self-regulation needs. It is also critical to understand the strengths of Autistic girls and gender diverse young people alongside any challenges that they experience.

3. Autism specific mental health support

“Our desire to fit that mould means we do mask a lot of ourselves and we do hide who we truly are to try and fit that. I think becoming yourself is a big journey that takes a lot of work and a lot of self-acceptance that we so badly want to fit that neurotypical mould that when we realise that we can't, there's a lot of mental juggling that we have to do”

The third priority area identified the imperative for research to better support the mental health of Autistic girls and gender diverse young people. This includes further understanding the impacts of misdiagnosis, social pressures, masking and burnout on their mental health. There is also a need for mental health providers and services to be markedly more knowledgeable of, and responsive to the needs of Autistic girls and gender diverse young people. This includes adapting therapeutic support programs and co-produced staff training that reflects, and better supports their needs.

4. Autistic friendships and relationships

“I can get very stressed with too much social stuff, which is hard because I’m actually a very social person... If I spend a lot of time with people I have to take a few days to recover”

The fourth priority area focuses on the need to better understand the social experiences of Autistic girls and gender diverse young people. This includes the importance of connections with other Autistic people, as well as challenges such as bullying, and being made to feel different and “like we don’t belong”. It is also important to develop Autistic led programs that support safe and lasting social understandings and connections for Autistic girls and gender diverse young people.

5. Experiences of gender diversity

“Focus on support first”

The fifth priority area outlines the need for research that focuses on acceptance of gender diversity within Autistic girls and gender diverse young people, as well as what supports they want, rather than investigating why they may not identify with the gender binary. Including Autistic gender diverse young people in research is also critical, to ensure that it is meaningful to their lives and meets their individual needs.

6. Accommodations to make life easier for us

“I spent years struggling in school until I mentally broke. I think this is an issue that needs to be addressed. Why does it take so long to help Autistic females, why do we have to be mentally exhausted”

The final priority area identified the need to focus on making life easier for Autistic girls and gender diverse young people. This includes re-evaluating the current diagnostic process to allow for earlier identification, expanding society's stereotypical view of autism, having Autistic pride, being accepted, accessing and receiving supports and including diverse Autistic voices in research.

8 key research areas were identified by Autistic women and gender diverse adults

1. Understanding and supporting specific needs in adulthood

"It's like once you're out of nappies no one's interested...No one wants to know about an Autistic adult"

The first research priority area for Autistic women and gender diverse people focuses on the necessity for understanding autism across the lifespan. This includes everyday life experiences and those related to parenting, relationships, friendships, as well as challenges such as homelessness, household management, employment and financial insecurity. Additionally, it highlights the urgent need for increased access to support, particularly co-designed support programs.

2. Experiences of trauma, abuse and sexual violence

"How to avoid the continual pattern of repeated trauma in Autistic women's lives"

The second priority area highlights the importance of understanding the experiences and impacts of trauma, abuse and sexual violence in Autistic women and gender diverse people and the urgent need for research to focus on prevention and providing trauma informed care and support. This is critical to ensure the safety of Autistic women and gender diverse people in society.

3. Supporting mental health and wellbeing

"I have had years of [Cognitive Behaviour Therapy]... all that sort of therapy has never worked. And they didn't take into account when I mentioned, the lights are so bright in the shops and the noise is too much... I was always told that was anxiety. No, it's not anxiety, it's actually sensory overload"

The third priority area outlines the need for supporting the mental health and wellbeing of Autistic women and gender diverse people across the lifespan. This includes understanding their experiences of mental health, misdiagnosis, Autistic burnout, meltdowns and shutdowns. Furthermore, there is a need for the development of co-designed therapeutic supports and Autistic led models of wellbeing, and for current therapeutic approaches to be adapted to meet the little explored care needs, preferences and priorities of Autistic women and gender diverse people.

4. Addressing barriers in healthcare

"They are not seeing it, they are not taught it. I don't believe they have the education... I feel that's a big area that needs somehow needs changing"

The fourth priority area emphasises the need for further research into the barriers and health inequities experienced by Autistic women and gender diverse people within society and the health care system itself. This includes understanding their experiences of navigating, accessing and

receiving medical care. There is also a significant need to increase health professionals understanding of Autism, to prevent medical gaslighting and diagnostic overshadowing. This is critical to enable practitioners to meet the needs of their Autistic patients and provide timely, effective, respectful and safe healthcare.

5. Understanding and supporting physical health needs

“A lot of my chronic health issues were not being treated. And I had really severe issues. I was going in and out of hospital . . . and nobody was doing any aftercare . . . I was on medication that did nothing. Nobody ever took me aside and said, this is not good enough. We need to up the ante”

The fifth priority area focuses on the importance of recognising and supporting the physical health needs of Autistic women and gender diverse people, with a better understanding of their experiences of ageing, sexual and reproductive health, pregnancy and childbirth, menstruation, and menopause. It is also an imperative to better understand their unexplored reactions to treatments and medication and their different presentations of co-occurring health conditions and pain. This will contribute to reducing the high levels of preventable illness and shorter life expectancy for Autistic women and gender diverse people.

6. Addressing barriers in education and the workplace

“It always seems to be the very data, analytical, puzzle loving guy... advertising, researching and understanding only those sort of Autistic people, is leaving behind all kinds of people who aren't like that... I end up feeling like, if I'm not that kind of person, is there any upside to my own 'autism' within a job? I also wonder how many other... girls out there feel the same way”

The sixth priority area identified the need to focus on the experiences of Autistic women and gender diverse people within the higher education system and the workplace. There is a need to further understand the existing barriers and gaps within these environments, and how employees, teaching staff, leadership and policy makes can support Autistic adults to participate and succeed in higher education and sustained employment. This will enable Autistic women and gender diverse people to experience financial, vocational and life autonomy and fulfillment.

7. Understanding the role of society, embracing neurodiversity and the importance of Autistic identity

“I think these girls, these strengths and these brains need to be embraced and utilised. I look at ... these brilliant, brilliant human beings... I wished that I had those tools, and that I was allowed to thrive and to be who I am when I was that young”

The seventh priority area highlights the need to better understand the impact society has on the experiences of Autistic women and gender diverse people, including the trauma caused by existing in a world that isn't designed for us. There is a need to embrace neurodiversity as the framework by which we celebrate, accept and support Autistic people and their way of being. Furthermore, there is need to focus on the important role that Autistic identity, community and culture plays in the pride, belonging and wellbeing of Autistic people.

8. Co-designing research and supports with Autistic people and ensuring intersectional identities and harder to reach groups are included

“Research on understanding it from the autistic perspective rather than layering that non-autistic perspective over the top”

The final priority area identified by Autistic women and gender diverse people focuses on the need for Autistic people to be an integral part of the design, implementation of autism research, services, programs, funding and supports. There also needs to be an emphasis on the importance of including Autistic people’s voices in these discussions, and ensuring input and outcomes reflect the diversity and intersectionality within the Autistic community.

It is critical that these research priority areas are included in the National Autism Strategy, to ensure this work meets the needs of Autistic girls, women and gender diverse people in Australia.

For more information on these research priorities please visit our webpage:

<https://www.uts.edu.au/Autistic-women-and-girls-research-priorities>

A full report titled *‘Nothing about us, without us’: Research priorities for Autistic girls, women and gender diverse people in Australia* is currently under peer review and will be provided once it has been accepted for publication.

Research Paper: ‘Living in a world that’s not about us’: The impact of everyday life on the health and wellbeing of autistic women and gender diverse people

We recently published a paper which focuses on the impacts of everyday life on the health and wellbeing of Autistic women and gender diverse people. We identified three main ideas or themes.

The first theme was about ‘all the stuff that you have to do to get through life’ such as cleaning, shopping, managing finances, parenting, managing periods, menopause, pregnancy, childbirth and physical health.

Our second theme showed the effect that everyday life has on Autistic women and gender diverse people. This included being overwhelmed by navigating public spaces, fitting with expected gender roles and the impact of ‘living in a world that’s not about us’ on mental health.

The final theme highlighted the positive impacts of being Autistic and connecting with other Autistic people, and the importance of including Autistic people in research.

Our findings highlight the need for better interactions with healthcare professionals, access to the right services, and changing attitudes in the community and society. These changes are critical to support the positive health and wellbeing of Autistic women and gender diverse people.

More information can be found here:

<https://journals.sagepub.com/doi/full/10.1177/17455057231189542>

Summary

The findings of our research, which represent the perspectives of 458 Autistic women, girls and gender diverse people, offer valuable insights into the everyday experiences, needs, policy, systemic and societal barriers that impact Autistic women, girls and gender diverse people in Australia. The inclusion of, and focus on, these priority areas within the National Autism Strategy, through targeted research efforts and policy and funding development, has the potential to transform the lives of Autistic women, girls and gender diverse people in Australia.