

Recommendations from the 2021 ASfAR Health, Wellbeing and Suicide Prevention in Autism Conference and Roundtable

This is a call to action for governments to take a position of leadership and address the problem of suicide and suicidal burden within the autistic community.

POLICY RECOMMENDATIONS

Social and Cultural

1. Mental health and research organisations must adopt a commitment to build autistic culture and identity that is distinct from neurotypical culture, and which must be adopted across mental health and research organisations. Initiatives that support the development of an autistic cultural identity must be both general (e.g., improving education about neurodiversity) and specific to autistic people (e.g., enhancing services and supports tailored to the needs of autistic people).

Structural

2. Entrench co-design principles in all new mental health policy and service delivery initiatives, with government authorities and mental health services taking proactive steps to involve autistic people from the outset.
3. Improve post-diagnostic services by linking newly diagnosed autistic people and the families of autistic children to local supports, including peak bodies, autistic led organisations and peer support networks.
4. Create and promote a Community Representation Code of Practice to ensure collaboration and empowerment of autistic people and those with lived experience in decision making and leadership roles in all aspects of mental health systems. This includes representation on service provider Boards of Governance and their respective sub-committees and community advisory committees.

Recommendations continue ...

- **Suicide** is the leading cause of premature death of autistic people of average IQ or above¹⁻⁵ up to seven times higher risk compared to the general population^{6,7}.
- With up to 24,535 suicide deaths in 2019, autistic people represent up to 3.2% of suicide deaths globally⁷.
- Up to half of autistic people will attempt suicide during their lifetime; at least 90% will have a co-occurring mental health condition^{5,8,9}.
- Autistic, and otherwise neurodivergent people, are not currently recognised as a priority group for suicide prevention activities and funding.

This Brief draws on the latest national and international research and from the content and survey feedback from two recent events:

1. The world first *Health, Wellbeing & Suicide Prevention in Autism: Bringing Autistic People, Researchers and Health Professionals Together* conference, and
2. A Post-conference Roundtable held in December 2021. Those with lived experience were deeply involved in the planning of the two events, in the discussions and formal presentations, and in the writing of the resulting Report.

The writing of this Brief was truly collaborative; formal and informal discussions during the Roundtable, conference forums, and with conference attendees, family members, autism and mental health clinicians, academics, experts, and keynote speakers, inform its content.

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POLICY RECOMMENDATIONS

Research

5. Establish and resource a research fund dedicated to exploring the intersections of mental health, suicide prevention and autism.
6. Undertake Autism Research Priority Consultation to identify priorities that are relevant to the health and wellbeing of autistic people and will directly inform practice. These priorities should then take precedence for funding.
7. **Acknowledging the need for further community consultation in the future, as a first step, the following candidates for health, wellbeing, and suicide prevention research prioritisation were identified through public consultation as part of the Conference and Roundtable:**
 - 7.1. Autistic burnout as a potential risk factor for suicidal behaviour.
 - 7.2. Accurate and timely diagnosis is an essential step toward receiving appropriate treatment; improvements are needed to autism diagnostic tools to reflect the profiles and needs of adults, women, non-binary and trans people.
 - 7.3. The validity and usefulness of framing autism as a culture (instead of a medical disorder).
 - 7.4. Validation as a protective factor in mental health promotion.
 - 7.5. Intersectional groups and identities within the autistic community (e.g., First Nations, LGBTQIA+).
8. Introduce a Co-design Code of Practice for all autism research. This must include a guide on flexible and individualised collaboration strategies relevant to context and stakeholders.
9. Increase training within higher education and professional development settings to ensure rigorous research design that includes a science translation plan.
10. Introduce an International Open Science Incentive Program to encourage researchers to use Open Science Frameworks and publish pre-registered studies.
11. Grant applications that involve the autistic community should demonstrate how the proposed study contributes to the health and wellbeing of autistic people, not simply how it contributes to furthering the literature.
12. Through government and other grant bodies, encourage researchers and clinicians/educators to collaborate and create resources that translate research into practice guidelines. To expedite this process, consider adopting best practice guidelines to ensure collaboration occurs at the commencement of any research project, prior to research findings being published in a journal.
13. Improve how research into mental health and autism is translated into clinical practice by embedding collaborative practice between researchers, clinicians and educators at the commencement of any research project, and prior to research findings being published in a journal.
14. Develop a searchable database of research findings and their translation into clinical practice.

Education and Training

15. Build a broader understanding of positive autism identity and respect for autistic culture across all levels of education by embedding practices that enhance cultural awareness, competence and humility.
16. Work with university accreditation bodies to include coursework covering autism affirming practices, presentations of autism in adults, intersectionality, and appropriate clinical practice in medical and allied health degrees. This coursework must strive to impart a foundational understanding of autism and form the basis of future clinical education.
17. Continuing professional development (CPD) providers should work with autistic people, researchers, and specialists to co-design accredited training offerings for allied health, education, medical and nursing professionals, that:
 - 17.1. Accrues against each participant's annual CPD requirements for registration.
 - 17.2. Centres autistic voices and lived experience and introduces participants to understanding autism as a valid culture, not solely a disorder.
 - 17.3. Develops clinical practice and professional skills for working with autistic people.
 - 17.4. Covers general topics of autistic burnout, mental health first aid, common co-occurring conditions (e.g., depression, anxiety, eating disorders) and their presentation in autistic people.
 - 17.5. Introduces a nuanced understanding of autistic burnout and its implications and management, and for those working in health and related fields, its differentiation from depression.
 - 17.6. Can be tailored to the specific needs of service providers working with minority groups that have high autism prevalence (e.g., LGBTQIA+ service providers).
18. Using the Community Representation Code of Practice, autistic and non-autistic clinicians, researchers, consumers and stakeholders should work together to expand existing suicide prevention programmes to develop training for suicide prevention and risk assessment that is specific to autism.

Background

Suicide attempts and deaths in autistic people is **three- to almost nine-fold** greater than that seen in non-autistic people^{3,5}. Worryingly, autistic suicide attempts and deaths begin to outstrip those seen in non-autistic people in the 10 to 19 age range⁵, and suicide ideation (thoughts about suicide) appears to occur at an even higher rate than implied by actual attempts or deaths¹⁰⁻¹². Within the autistic community, co-occurring psychiatric illness and ADHD appear to mark out those at particular risk^{14,5}. Autistic suicidality differs from trends seen in the general population, with the typically protective effects of romantic relationships, greater age, educational attainment and employment attenuated or even absent⁵.

Social Context: Autistic culture, intersectionality and co-design for research and practice

“Understanding autism and the culture of autistic people, so autistic people do not have to mask/camouflage their autism, is suicide prevention.” - Lisa Morgan, suicide prevention expert, autistic author¹⁴

While **Autistic Culture** is not a new phenomenon among the autistic community, it rarely makes it into academic discourse or clinical practice⁵. Research presented at the Conference suggests that mental health professionals and clinicians could do better to listen to the experiences of autistic people and to validate these experiences^{15,16}. Recognising and valuing the differences of autistic people in addition to viewing autism as something that does not require ‘fixing’ is critical to the prevention of systematic discrimination and stigma which likely to contribute to the mental health difficulties and high rates of suicide they experience.

Intersectionality - each autistic person has an individual experience and place in society that affects their experiences of the world. An autistic person may also have an intellectual disability, be non-verbal, a person of

colour, a person of cultural and linguistic diversity, have co-occurring conditions such as ADHD, be part of the LGBTQA+ community, experience employment insecurity, insecure housing, or be a victim of interpersonal violence. Thus, multiple factors affect the presentation and supports required on an individual level.

“Autistic experiences of mental health and suicidality, stress and crisis are different, and they really need to be recognised as different to non-autistic people.” -Dr Susan Hayward, autistic academic and Roundtable co-chair

Co-design for research and practice - it is pivotal that the autistic voice is included in the development, design, governance, and implementation of mental health and suicide prevention strategies as it acknowledges that their experience is distinctive, is culturally unique and intersectional in nature. Embracing participatory and co-designed supports can have wide-ranging benefits:

- The research is relevant to the consumer
- It builds public awareness of, and support for, science and research, that acknowledges the lived experience
- Improves public confidence in research through improved openness and transparency
- More effective translation of research to deliver improved mental health outcomes
- Increased opportunities to continuously improve the quality and impact of research

“Let us help you help us. We know autism. We are autistic. We know more about the reality of living with autism in today’s society than people who have worked with autistic people for any number of years. No amount of education, work experience, knowledge about autism or even research findings can measure up or compare to lived experience.” - Lisa Morgan, suicide prevention expert, autistic author

We acknowledge and remember all persons lost to us because of suicide as well as the people left behind. We acknowledge the enduring suffering suicide brings and the complex emotions and experiences of all people who have contemplated suicide. We acknowledge that those with lived experience can provide hope, resilience, and support to those at risk.

Research Directions and Translation

Specific research topics and research to practice timelines were discussed throughout the ASfAR Conference presentations, question times, and at the Roundtable. The following priorities were identified for future research and practise.

1. **Autistic burnout** - a better understanding of the construct and its impact on quality-of-life, relationships, work, and employment, and on the broader community is required.
2. **Suicide protective factors** - it is important to identify potential protective factors. In particular, there may be factors that are especially salient to autistic people or differ from those of non-autistic people.
3. **Suicide prevention messaging** - suicidal behaviour, including attempts, can present in very young autistic children. Therefore, it is recommended that awareness and prevention efforts begin early, during the school years.
 - 3.1. Autistic people should be identified in the National and State suicide policies as a population of concern.
 - 3.2. Aspire to a reduction of 10% of suicides amongst the autistic population over 5 years.
4. Evidence-base for autism specific (not simply adapted for use) interventions and supports are expanded to understand - **what works for whom?**
5. **Universal design** of supports, services and interventions - flexible, equitable use and access, effective information communication, the presence of simple and intuitive features, low effort, and appropriate.
6. **Translation to practice** - optimizing timeframes from research finding to practice. Research translation must be considered a quantifiable research outcome.

Training and Education

There is a lack of knowledge and understanding of autism by professionals and the wider community, and how mental ill health and suicidality look like for autistic people. This interrupts professionals from developing effective communication with autistic people and from developing confidence in selecting suitable interventions and supports. The following sections discuss areas of training were considered imperative by Roundtable participants:

- The cultivation of both **cultural humility and competence** in professional practice and the training of educators to incorporate cultural humility as a universal element underpinning social development.
- Any **measurement tools** used in autistic populations must be psychometrically valid assessments of the construct they are designed to capture, as well as encompassing aspects of the construct that may be unique to the autistic perspective.
- **Autism specific education** and training must be incorporated into the regulatory structure of professions offering mental health and suicide prevention services.
- The mental health sector must take responsibility for the mental health and wellbeing of the autistic population.
- Frontline professionals must develop **confidence in working with autistic and otherwise neurodivergent people**, in their presentations during distress and crisis, and in the overlap of autism and mental ill health.
- **Autistic researchers and professionals** must be supported in their studies to improve their representation in the workforce.

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