May 2022

Recommendations from the 2021 Australasian Society for Autism Research “Health, Wellbeing and Suicide Prevention in Autism” Conference and Roundtable

Chairs: Darren Hedley, Sarah Cassidy, Chris Templin, Susan M. Hayward

Members: Erin Bulluss, Jacquiline (Jac) den Houting, Kairi Kõlves, Brenna B. Maddox, Lisa Morgan, Rachel Moseley, Aspasia Stacey Rabba, Axel-Nathaniel Rose, Mark A. Stokes, Robyn L. Young

Report compiled by: Alex Haschek and Ensu Sahin

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.

In this document we use identity-first language as it is the preference of the autistic members of the Roundtable. Research has shown that many people with lived experience of autism prefer the use of identity-first rather than person-first language[1]. We acknowledge that some people with a diagnosis of autism prefer person-first language.

Suggested Citation

Hedley, D., Cassidy, S., Templin, C., Hayward, S. M., Haschek, A., Bulluss, E., Den Houting, J., Kõlves, K., Maddox, B. B., Morgan, L., Moseley, R., Rabba, A. S., Rose, A., Stokes, M. A., and Young, R. L. (2022). *Recommendations from the 2021 Australasian Society for Autism Research "Health, Wellbeing and Suicide Prevention in Autism" Conference and Roundtable*. La Trobe University, Melbourne. Doi 10.26181/19690432

---

[1] Bury et al., 2020; Kenny et al., 2016

Foreword

Professor Andrew Whitehouse, President, Australasian Society for Autism Research

The Australasian Society for Autism Research (ASfAR) exists to help connect researchers across the Australasian region to discuss and conduct research that positively impacts the lives of autistic individuals. The incredible conference on mental wellbeing and suicide prevention in autism is a brilliant example of this.

The high rate of mental health difficulties among autistic individuals has been known for many years. However, while two decades of research has helped to describe and quantify the breadth and scale of the mental health challenge, solutions to promote mental wellbeing have not nearly been as forthcoming. ASfAR was very proud to support this Conference and the Roundtable, and hopes that the connections formed, and recommendations provided in this report, lead to lasting, positive impact on the autistic community and the world.

Parliamentary Secretary for Mental Health and Parliamentary Secretary to the Premier, Victoria, Mr Steve Dimopoulous

It is my pleasure to provide a foreword to this landmark report on health, wellbeing and suicide prevention within the autistic community. I would like to acknowledge the work of the conference and roundtable conveners and chairs in bringing the events and this publication together, and the national and international representatives who contributed to the discussions and to the production of this report.

I would also like to acknowledge the speakers and attendees at the ASfAR Health, Wellbeing and Suicide Prevention conference, and in particular the valuable contribution of those with lived experience. I want to thank you for your leadership in this area, but more so for the guidance you offer to the mental health system and your continued advocacy for its improvement.

In 2021 The Royal Commission into Victoria's Mental Health System handed down its final report. The Commission engaged in two years of detailed consultation, with over 1600 stakeholders and 12,500 contributions from individuals and organisations, including many autistic people and autistic organisations. Its report was landmark and gave a detailed roadmap to reform the mental health system.

The testimonies the Commission received highlighted the work we must do as a community, as research partners, and as government, to address the experience of isolation and disconnect of many people within the mental health system. As a government, we are designing a new system which will place the expertise of people with lived experience at the centre of the care provided, including consumers, carers, family, and supporters. This new system will prioritise accessibility and ensure people from all backgrounds and circumstances can readily access appropriate treatment, care and support when these are needed. Our collaboration with research partners, service providers, non-government organisations and other players and contributors in civil society, including the workforce, is central in being able to deliver these reforms.

We are committed to building a system that is welcoming to neurodivergent people. There is a high correlation between autism and co-occurring mental health conditions, and there are a range of gaps in the service system that autistic people experience every single day. A refrain that was repeated throughout the conference was that *'Autism is core business for mental health'*. I firmly believe that if we design and steward these reforms with the needs of neurodivergent people in the front of our minds, the benefits will be universal and will support all consumers.

The Victorian Government recently launched its new State Disability Plan – *Inclusive Victoria 2022-2026*. As with this report, the key themes focusing on an intersectional approach, and of co-designing research and policies to give people with disabilities a voice in what impacts them were heard often. The Victorian Government listened and has taken it to heart, with making intersection approaches and co-design two of the six areas of systemic reform in the new plan over the next four years.

The ASfAR conference and roundtable event were successful in raising awareness of the specific mental health needs of autistic people. Future systems need to be cognizant of all the risks and vulnerabilities and must treat people in the fullness of their humanity. Thank you so much for the work you do in collaboration with the autistic community. We look forward to continuing to partner with you over the course of delivering these reforms.

Executive Summary

The issue

Suicide is the leading cause of premature death of autistic people[2]. Autistic people face an up to seven-fold higher risk of premature death by suicide compared to the general population, with overall higher risk reported for autistic females compared to males.[3] Suicide and suicide-related behaviour (e.g., suicide attempt, self-harm with suicidal intent, suicidal ideation, suicide plan) are also highly prevalent in autistic people; thus, the psychological burden of suicide is pervasive among this priority group affecting all aspects of life[4]. This burden is felt across the lifespan, with research from Canada and Australia finding that autistic children as young as seven have made a suicide attempt[5]. There is also an exceptionally high prevalence of **co-occurring mental health conditions** within the autistic community.

Rates of clinical anxiety are estimated to be around 40% in children and 60% in adults, and current and lifetime depression is 26% and 40%, respectively[6]. Of the approximately 48% of autistic adults who attempted suicide in their lifetime, up to 90% had a co-occurring mental health condition[7].

The intersection of mental health conditions and autism, as well as other factors such as gender diversity - a high proportion of autistic people identify as sex/gender diverse[8] - may increase suicide risk in the autistic population. It is imperative that the health and wellbeing of autistic people are placed at the forefront of the political agenda. Autistic and otherwise neurodivergent people are not recognised as a priority group for suicide prevention activities and funding. This document outlines a case for recognition of the autistic population as a priority group for suicide prevention research, funding, and prevention programs.

This report was compiled with international leaders and researchers in the fields of autism health and wellbeing, suicide prevention research and policy, and people with lived experience. It is intended to:

1. **Raise awareness of the increased suicide risk within the autistic community.**
2. **Identify gaps in research and practice.**
3. **Identify solutions and a course of action to reduce suicide-related behaviour and death by suicide within the autistic community.**

This document represents a call to action for international governments and instrumentalities to take a position of leadership and address the problem of suicide and suicide associated distress within the autistic community.

---

[2] of average IQ or above; Dietz et al., 2020; Hill, Witt et al., 2021; Hirvikoski et al., 2016; Kirby et al., 2019; Kõlves et al., 2021
[3] Hedley, Stokes et al 2022; Santomauro et al., 2021
[4] De Leo et al., 2021; Goodfellow et al., 2019; Hedley & Uljarević, 2018; Hirvikoski et al., 2016; Kirby et al., 2019; Sahin et al., 2021
[5] Sahin et al., 2021
[6] Hollocks et al., 2019; Kent & Simonoff, 2017; Murray et al., 2019; Thomas et al., 2017; Uljarević et al., 2020
[7] Kõlves et al., 2021; Moseley et al., 2021; Sahin et al., 2021
[8] Sex and gender divergent people are also a priority group for suicide behaviour; George & Stokes, 2018a

Background

"We are still not getting it right, because the rates are still too high"

Mel Spencer, CEO, Different Journeys

Researchers internationally recognise an occurrence of suicide attempts and deaths in autistic people that is three- to almost nine-fold greater than that seen in non-autistic people[9]. With up to 24,535 suicide deaths in 2019, autistic people comprise up to 3.2% of suicide deaths globally[10]. Autistic suicide attempts and deaths begin to outstrip those seen in non-autistic people in the 10 to 19 age range, and suicidal ideation (thoughts about suicide) occurs at an even higher rate than suicide attempts or deaths[11]. Within the autistic community, co-occurring psychiatric conditions appear to mark out those at particular risk[12]. Although some individual studies are less conclusive[13], when data are combined across studies, suicide risk is higher in cisgender autistic women than autistic men, and lower in autistic people with intellectual disability[14]. 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 absent[15].

Intrapersonal risk factors that may be associated with autistic suicidality include alexithymia, emotion dysregulation, rumination, low self-esteem, camouflaging efforts (concealing autistic traits or behaviour), communicative impairments and cognitive inflexibility[16]. Interpersonal risk factors have likewise been identified, including unmet support needs and loneliness[17]. Attempts to ground these disparate findings in a more cohesive theoretical framework have focused on testing hypotheses from the interpersonal theory of suicide[18]. These studies indicate there is value to be derived from this framework, most notably in the potency of feelings of burdensomeness as a correlate of suicide ideation and attempts[19]. They also indicate that life experiences which erode an individual's fear of death may partially create 'capability' for suicide attempts. However, findings from these studies reflect that this theoretical approach is insufficient to understand and predict autistic suicidal ideation and attempts. There is a need to examine other suicidogenic factors, such as feelings of entrapment and defeat, and to explore suicidality longitudinally as a fluid process, influenced by stable and dynamic features that determine risk at any time point[20].

---

[9] Hirvikoski et al., 2016; Kõlves et al., 2021
[10] Santomauro et al., 2021
[11] Cassidy et al., 2014; Conner et al, 2020; Kõlves et al., 2021; Pelton et al., 2020a
[12] Hand et al., 2020; Kõlves et al., 2021
[13] e.g., Hand et al., 2020; Hirvikoski et al., 2016, 2020; Kirby et al., 2019; Kõlves et al., 2021; Pelton et al., 2020a
[14] Santomauro et al., 2021
[15] Kõlves et al., 2021
[16] Arwert & Sizoo, 2020; Cassidy et al., 2018, 2020; Connor et al., 2020; Costa et al., 2020; Paquette-Smith et al., 2014; Richards et al., 2019; South et al., 2020
[17] Cassidy et al., 2018; Hedley et al., 2018
[18] Van Orden et al., 2010
[19] Dow et al., 2021; Moseley et al., 2021; Pelton et al., 2020a
[20] Bryan et al., 2020; O'Connor & Kirtley, 2018

Our approach

In making evidence-based recommendations, we draw on the latest national and international research and from the content and survey feedback from two events held in December 2021:

1. The world-first *Health, Wellbeing & Suicide Prevention in Autism: Bringing Autistic People, Researchers and Health Professionals Together* Conference (funded by ASfAR; Appendix A).
2. ASfAR Post-Conference Roundtable (Appendix B).

These activities, and the associated formal and informal discussions during the Roundtable, Conference forums, and with Conference attendees, family members, autism and mental health clinicians, academics, lived experience experts and keynote speakers, inform the content of this Report. The writing of this Report was collaborative; 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 Report. We hope that this Report will be used to inform policy and decision making, addressing the mental health and wellbeing needs of autistic people worldwide.

Summary

Social Context was discussed during these events as embedding health and wellbeing within the broader socio-cultural environment. Three fundamental philosophical ideals emerged:

1. Recognition of autistic culture.
2. The intersectional nature of experience for autistic people.
3. The importance of co-design for research and practice.

Specific **Research Directions and Translation** to practice isolated the following points:

1. The importance of autistic burnout and its implications for clinical supports.
2. Suicide protective factors.
3. Suicide prevention messaging.
4. The experience of suicidal thoughts and behaviour, intervention targets, trauma, and non-suicidal self-injury.
5. What therapy suits which person? Can this be predicted?
6. Universal design of supports, services, and interventions.
7. Translation of research into practice.

Specific **Training and Education** directions were identified during discussions:

1. Cultural humility and competence.
2. Appropriate use of assessment tools.
3. Importance of including autism-specific tertiary education and professional development.
4. Building responsibility and confidence in frontline professionals.
5. Identifying mental ill health and crisis in autistic people.
6. Supporting aspiring autistic professionals and researchers in their studies.

Recommendations for reform

Drawn from the conference and subsequent roundtable discussions, a suite of reform recommendations has been co-designed to drive improvements in how autistic people can access quality, tailored support for mental health conditions, and to ensure the research agenda into mental wellness and suicide prevention for autistic people remains focused and current.

Social and Cultural

1. Mental health and research organisations must adopt a commitment to build autistic culture and identity that it 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.

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.

1. Social Context

The following section outlines three fundamental philosophical ideals discussed during the Conference and Roundtable: (1) autistic culture, (2) intersectionality and (3) co-design. Each of these ideals reflects an interaction between the individual and their environment; thus, health and wellbeing are firmly embedded within the broader socio-cultural environment.

1.1. Autistic culture

Culture is "*the way of life of a people, including their attitudes, values, beliefs, arts, sciences, modes of perception, and habits of thought and activity*[21]". While autistic culture is not a new phenomenon among the autistic community[22], it rarely makes it into academic discourse or clinical practice[23].

> "First, to disengage from the idea that autistic people have a disorder or condition and need help to be less autistic, or more like non-autistic people - which is the same thing in different packaging - and instead recognise autistic culture as a valid phenomenon in and of itself. So, the very way that autistic people process information and therefore the way we experience ourselves and others in the world, differs on a neurobiological level and that's not wrong, it doesn't require fixing, but it does require acknowledgment as a form of culture in and of itself."

Dr Erin Bulluss, autistic psychologist, Lived Experience Panel member and Roundtable participant

Participants in the Roundtable agreed that recognising and valuing the differences of autistic people in addition to viewing autism as something that does not require 'fixing' are critical to the prevention of systematic discrimination and stigma experienced by autistic people. Over the life course, discrimination and stigma are likely to contribute to the mental health difficulties experienced by autistic people and the high rates of death by suicide relative to the general population.

> "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 author[24], Conference guest speaker and Roundtable participant

---

[21] Oxford Reference - https://www.oxfordreference.com/view/10.1093/oi/authority.20110901080526139
[22] Mesibov et al., 2004
[23] Bulluss., 2021
[24] Morgan, 2021 - https://autism-crisis-support.com

An example of how this presents is the pervasiveness of bullying of autistic students (58% of autistic youth without an intellectual disability (ID), 50% of autistic youth with an ID)[25]. Autistic people are victimised for autistic features before these are recognised as such, as is reflected in the accounts of late-diagnosed adults[26]. Bullying is associated with higher depression symptoms, suicidal ideation, and attempted suicide[27]. In the United Kingdom (UK), autistic adolescents receiving treatment for a mental health difficulty who also reported bullying in their first month were twice as likely to go on to develop suicidal thoughts and behaviours[28].

It is vital to shift the responsibility onto those who are not autistic to develop adequate competence in autistic culture and to cultivate cultural humility, defined as a life-long commitment to reflecting upon and critiquing our own practices[29]. In practice, it means listening deeply to the experiences of autistic people and acknowledging that only *through lived experience* can one truly understand the experience of existing as an autistic person. 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[30]. We asked Conference participants *What are your top 4 take away messages from the Conference content?*

---

[25] Richdale et al., 2021
[26] Lilley et al., 2021
[27] Klomek et al., 2011 (general population study)
[28] Holden et al., 2020
[29] Tervalon & Murray-Garcia, 1998
[30] Benn et al., 2021; Denney et al., 2021

> "… listen to what autistic people have to say about their own MH[31] and Wellbeing."
>
> "Be humble, listen to the autistic person you are helping and believe what they say about themselves and their experiences."
>
> "(we need) To listen to the autistic person's needs and goals rather than trying to make them fit in with non-autistic society"

Autistic respondents to the Conference feedback survey

> "I think the core of it is that mental health professionals should be willing to listen to us. We are in general very good at self-advocating because we have to do that a lot."

Axel-Nathaniel Rose, Lived Experience Panel member and Roundtable participant

Cultural humility also includes building awareness of making assumptions from a position of being part of the dominant non-autistic culture. For example, how a person presents when in distress, or how an individual will express suicidal intentions.

> And when so much of mental health training is focused around being normal, normative work life, normative relationships, all these things are made for neurotypical people. Even if some people want to aspire to those things, great, but neurobiologically, many of us are not equipped for that and the way that we can be most healthy is by accepting that we are falling outside of the norms.

Axel-Nathaniel Rose, Lived Experience Panel member and Roundtable participant

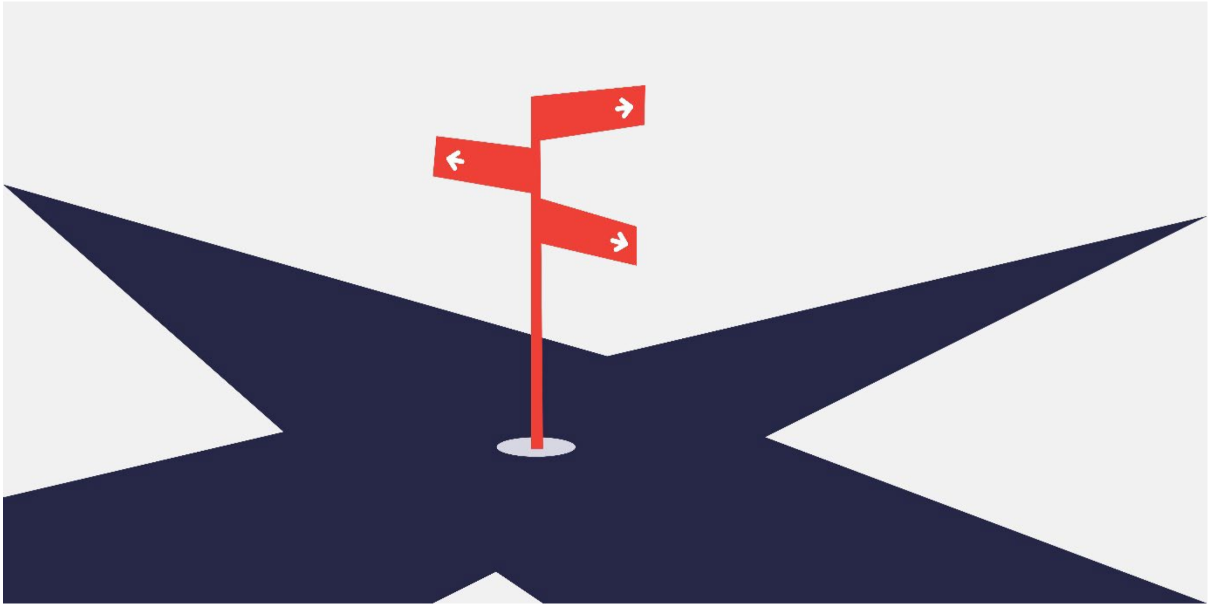
The advantage of adopting a cultural humility approach is that it is conceptual and can therefore be implemented systemically and universally; as a philosophical approach, it can be taught through education, training, and professional development initiatives.

---

[31] Abbreviation for mental health

Acknowledgement of the autistic community as a culture (i.e., similar to the approach taken toward other diverse cultures, for example, deaf culture) has the potential to lead to a shift in understanding of the experiences of autistic people by the health sector, with downstream benefits to healthcare, clinical and research practice.

1.2. Intersectionality



Intersectionality refers to the different aspects of a person's identity that can expose them to overlapping forms of marginalisation and discrimination[32]. The autistic experience is one of these identities. Each person has an individual experience and place in society that affect their experiences of the world. For example, 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[33]. Thus, multiple factors affect the presentation and supports required on an individual level[34].

> "… the intersection of autism and a mental illness is complex to navigate…how are they impacting each other? I have depression, anxiety, bipolar, and PTSD. Figuring out what is what is such a puzzle, for me and any clinician engaging with me."

Axel-Nathaniel Rose, Lived Experience Panel member and Roundtable participant

---

[32] Victorian Government, 2021
[33] Cooke et al., 2021
[34] Botha & Frost, 2020; George & Stokes, 2018b

Conference and Roundtable participants strongly voiced that individual intersecting identities need to be acknowledged and heard for healthcare (including mental health and suicide prevention strategies and supports) to be effective. This is critical for developing personalised healthcare and avoiding discrimination caused by systemic inequalities and discrimination that may be exclusionary to specific population segments. Acknowledgement of the intersection of autism, mental and other health conditions and different identities is therefore fundamental to avoiding discrimination and understanding suicide risk factors.

> "[There can be] double discrimination, in the meaning that they are discriminated in the context of autism but also in the context of having suicidal behaviours."

Prof Kairi Kõlves, suicide prevention expert and Roundtable participant

> "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. It is a complex issue to address; it does need systemic change."

Dr Susan Hayward, autistic academic, Lived Experience Panel moderator and Roundtable co-chair

> "… that idea of understanding the person, their background and cultural experience, and understanding and recognising autistic experience… is very important in then validating the ways that mental illness can present differently."

Dr Jac Den Houting, autistic academic, Lived Experience Panel member and Roundtable participant

Acknowledging the unique experiences of autistic people is an important step toward validating their experiences, which is a critical component of improving the lives of autistic people. Our research indicates that validation of experience is extremely important when seeking professional help for mental health concerns[35]. Many autistic people report that their experiences around autistic identity, diagnosis, or traits can be dismissed by mental healthcare professionals. This may lead to delays in autism assessment or diagnosis, their autism diagnosis or autistic traits not being affirmed by professionals, or professionals only minimally considering autism during treatment planning.

---

[35] Denney et al., 2021

Ultimately, clinical care cannot be effective without a respectful and trusting therapeutic alliance between the healthcare provider and client. Conversely, being open to, listening to, and acknowledging an autistic person's experience can go a long way toward building a trusting and mutually respectful alliance.

The Suicide Response Project (SRP)[36] www.suicideresponseproject.com, is a prime example of how important this approach can be in terms of clinical support and suicide prevention tools. The SRP was launched at the Conference and is one of the first education tools developed to address the intersectionality of mental wellbeing and suicide prevention, autism, neurodiversity, and gender diversity. The SRP was developed by a team of experienced researchers, academics, and psychologists and, most importantly, was co-designed with autistic and LGBTIQA+ people with lived experience of suicidal ideation as well as their families and people with lived experience of being bereaved by suicide or having supported someone after a suicide attempt. The SRP is an open source, freely accessible web-based education and training program designed to educate people about how to support someone who may be thinking about suicide or engaging in suicidal behaviour. This evidence-based program guides people through 12 modules on detecting and responding to suicide risk in others. Uniquely, it provides content specifically to supporting autistic and gender diverse people.

---

[36] Hill, Chan et al., 2021

1.3. Co-design for research and practice

In acknowledging that the autistic experience is distinctive, is culturally unique and intersectional in nature, it is therefore pivotal that autistic voices are included in the development, design, governance, and implementation of mental health strategies.

> "Let us help you help us. We know autism. We are autistic. We know more about the reality of living with autism in 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, Conference guest speaker and Roundtable participant

> "Respecting that voice and elevating that lived experience"

Chris Templin, Amaze Senior Policy Analyst, Policy, Clinical practice and Service Provision Panel moderator and Roundtable co-chair

> "Autistic people need to be part of the solution"
>
> "More people with autism need to be involved in education, research and care for people on the spectrum"
>
> "Professionals need to understand not only autism, but living with autism"

Respondents to the post-Conference survey

Embracing participatory and co-designed supports can have wide-ranging benefits:

- Undertaking research that is relevant to the autistic community's needs.
- Building public awareness of, and support for, science and research, that acknowledges the value of lived experience experts.
- Improving public confidence in research through improved openness and transparency in the conduct of research.
- Translating research more effectively to deliver improved mental health outcomes.
- Preventing an 'us versus them mentality' by working in cooperation.
- Increasing opportunities to continuously improve the quality and impact of research.

As one example, a recently released co-designed workplace mental health training package was presented at the conference[37]. The researchers found co-development of the programme and inclusion of lived experience expertise led to improvements at all stages of the development process:

- Increased emphasis on workplace culture, diversity, inclusion, bullying and workplace barriers.
- ADHD described as a co-occurring condition not a mental illness.
- Language emphasis on strengths-based language, more user-friendly language.
- Inclusion of autism-specific examples.
- Changes to layout to improve accessibility (e.g., glossary, breakout boxes).

However, when collaborating, it is important to fully understand the potential burden this carries for autistic people[38].

> "… autistic people also experience burnout and distress as part of their involvement and advocacy in trying to do this kind of work. It is a form of emotional labour. So, it is a very tricky balance - as we all agree that autistic experiences need to be centred, but we also must be extremely careful in how we ask and that we do not ask too much... how to manage that balance?"

Dr Rachel Moseley, Lived Experience Panel member and Roundtable participant

---

[37] Bury et al., 2021

[38] Botha, 2021; Lory, 2019; McKeown, 2021

2. 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 practice.

2.1 Autistic burnout

Autistic burnout was one of the most discussed topics during the Conference and the feedback survey. Autistic burnout is a term used to describe a state of emotional, physical, and mental exhaustion that develops over time when the demands on a person exceed their capacity[39]. Often first experienced in childhood or adolescence, it can reoccur in adulthood, lasting for months or years, and with some never fully recovering[40]. A widespread lack of awareness and acceptance of autism diversity in social, health care and employment systems contribute to the onset and reoccurrence of burnout, often due to masking - attempting to hide or conceal one's autistic behaviours to 'fit in' with non-autistic groups.

There is a lack of research in this space.

> "It's very difficult, there were lots of periods of time where I feltlike I was in burnout. But you just keep going because you have no choice, I am the only person that can look after my daughter. So, I just have to push through."

Gilly-Elle, Lived Experience Conference Panel member

---

[39] Mantzalas et al., 2021; Raymaker et al., 2020

[40] Mantzalas et al., 2021

Opportunities to recover from burnout and exhaustion may be limited due to a lack of available supports.

> "Autistic burnout is one of the very commonly missed and misdiagnosed autistic experiences; most of the markers of burnout are also markers of depression. Clinicians who are not aware of autistic burnout… will miss autistic burnout and are likely to misdiagnose autistic people with depression instead."
>
> *Dr Erin Bulluss, autistic psychologist, Lived Experience Panel member and Roundtable participant*

Notably, the supports recommended for people experiencing autistic burnout vs. depression are different, and a lack of recognition can prolong a burnout episode making differential diagnosis fundamentally important.

1. **Autistic burnout** – it is crucial to reduce demands by slowing down, reducing pace, limiting masking behaviours, and resting as much as possible to regain capacity. Once some capacity is restored, the slow re-engagement of social connections, interests, and additional tasks of daily living can be encouraged whilst creating a lifestyle that reduces the likelihood of future burnout.
2. **Depression** – one of the common, evidence-based treatments for depression is behavioural activation, which involves scheduling activities that are pleasant and/or lead to a sense of accomplishment. While this is an effective approach for treating depression, taking this approach with someone in acute autistic burnout will extend

and/or worsen the period of burnout because demands are being increased rather than reduced.

3. **Autistic burnout and depression** – when individuals experience concurrent autistic burnout and depression (a common experience), burnout must be addressed first by reducing demands and promoting rest. Implementing a depression treatment can begin once the acute burnout has subsided.

Research suggests autistic burnout may be associated with a lower quality of life and wellbeing and poor mental health and risk of suicide[41].

> "For some autistic people, precursors to suicide may include exhaustion and autistic burnout"

Professor Mark Stokes, Health Autistic Life Lab, Deakin University and Roundtable participant

There must be more research into autistic burnout as a construct, as well as research investigating the potential impact of burnout on quality of life, relationships, work, and employment, and on the broader community.

2.2 Risk and protective factors

In considering suicide prevention it is important to identify potential risk and protective factors. There may be factors that are especially salient to autistic people or differ from those of non-autistic people. In addition to existing research,[42] new research findings presented at the Conference are briefly summarised below.

- **Social connectedness and social relationships.** Along with access to excellent quality mental health services and healthcare professionals, social connection and relationships are critical protective factors against poor mental health outcomes, including suicidal behaviour[43].
- **Safety planning and 24hr access to supportive communities or services, such as Lifeline or online communities.** Although not everyone will find all services helpful to them, many autistic people do find these services helpful when they are in crisis. It is therefore important to identify and explore what strategies and services are helpful to the individual[44].
- **Coping strategy selection.** The use of engagement coping strategies (e.g., problem-solving) was identified as a protective factor against poor mental health and wellbeing outcomes in autistic adults[45].

---

[41] Mantzalas et al., 2021; Raymaker et al., 2020
[42] Hedley et al., 2018; Hedley et al., 2021; Hedley, Hayward et al., 2022; Cassidy et al., 2018
[43] Denney et al., 2021
[44] Denney et al., 2021
[45] Muniandy et al., 2021

- **COVID-19 health restrictions.** Government restrictions during the second wave of the pandemic may have a protective effect on some autistic people, potentially due to reduced social stressors, and may include reduced stress, anxiety, and depression symptoms[46]. However, overall, the effects of the COVID-19 pandemic on autistic people have been found to be negative[47], affecting many aspects of life.
- **Improving self-determination** (perceived autonomy, competence, and social connectedness) may improve quality of life in autistic populations and may thus serve as a protective factor against poor mental health and wellbeing[48].

2.3 Messaging around suicide prevention

Research presented at the Conference indicates that suicidal behaviour, including attempts, can present in young autistic children[49]. Therefore, it is recommended that awareness and prevention efforts begin early, during the school years. The Roundtable members noted that there may be reluctance to discuss suicide and suicide prevention in a school setting due to fears of increasing suicide risk. However, general suicide prevention gatekeeper training conducted in school settings suggests this is not the case, at least in children completing Year 10:

> "We partnered up with Lifeline Australia to make sure that delivering [suicide prevention] training to young people in school settings didn't cause harm. What we found was that it did not cause harm, there was no evidence of an iatrogenic effect. Young people liked it and they found it acceptable, and it also increased their knowledge, their confidence, and their willingness to support others."

Professor Jo Robinson, Director of Orygen, Revolution in Mind youth suicide prevention research programs, Conference speaker and Roundtable participant

---

[46] Brown et al., 2021
[47] Hedley et al., 2021; Pellicano et al., 2021
[48] Andrews et al., 2021
[49] Sahin et al., 2021

2.3.1 Towards zero-suicide framework?

The Roundtable noted that governments in Australia, the United Kingdom, and the United States have each adopted a "towards zero" suicide policy within their suicide prevention frameworks[50]. The Roundtable agrees, however, that the priority for governments should be on the implementation of strategies and policy that can make an immediate difference. As one example, the Australian government suicide prevention taskforce prioritises improving access to immediate and effective support and connecting services, emphasising a need to empower professionals and the general community to recognise and respond to those in distress while instilling hope[51]. It was also noted that suicide prevention leadership needs to be supported within the autistic community to achieve a reduction in suicide deaths.

The Roundtable members call for all governments and instrumentalities to identify the autistic population as a priority group for suicide prevention.

2.3.2 Should we adopt a zero-suicide framework/messaging?

The Roundtable discussion identified that while zero-suicide was an inspirational goal, it was unlikely to be achievable. Thus, development of more realistic, measurable, and achievable goals is recommended. One group member noted that, in the autistic population, it may be important to

---

[50] Australian Government Department of Health, 2020; E.g., NSW; SA; QLD; WA; NT; TAS; VIC; Zero Suicide International, https://zerosuicide.org/; Zero Suicide International of Australasia - https://www.zerosuicide.com.au/

[51] Zero Suicide International of Australasia - https://www.zerosuicide.com.au/

develop aspirational goals alongside, or in concert with achievable goals (e.g., WHO[52]). Examples of achievable goals are:

- 10% reduction of suicides amongst the autistic population over 5 years.
- Reliable, nationwide reporting of emergency department and hospital presentations for non-fatal suicidal behaviour of autistic people.
- Reliable reporting of autistic suicide deaths[53].

Finally, it was noted that caution is required with any messaging concerning suicide, as some messaging may inadvertently have the effect of increasing suicidal behaviour or causing harm. It was further recommended that, in the first instance, it would be important to follow WHO media guidelines[54] concerning reporting of suicide. Importantly, the WHO guidelines encourage the presentation of positive stories, which can be inspirational, and avoiding the use of potentially stigmatising language. Overall, the group felt that more work was needed to investigate the advantages and disadvantages of promoting a zero-suicide framework outside of existing government messaging, and to review policies from other countries.

2.4 The experience of suicidal thoughts and behaviour, intervention targets, trauma, and non-suicidal self-injury

Factors that may be targets for suicide prevention intervention in the autistic community include burdensomeness, fear of death, beliefs and expectations around suicide, trauma, and bereavement. This topic was discussed in the ASfAR keynote presentation by Professor Batterham[55]. Burdensomeness, feelings of self-hate and being a liability to others, are associated with both suicidal ideation and suicide attempts over and above depression and anxiety; as in the general population this factor is purported to predict suicide ideation but not attempts, its association with suicide attempts in autistic adults suggests it may be a particularly potent factor to scrutinise in more depth and target clinically. Reduced fear of death was also associated with lifetime and past-year suicide attempts[56] in autistic adults. Relatedly, research from the general population[57] indicates that the beliefs and expectations that an individual holds about suicide may be influential to their behaviour and thus suicide risk. Trauma and post-trauma symptoms are highlighted in recent work[58] as predictors of suicidality in autistic people. Importantly, the kinds of events experienced and perceived as traumatic, and which result in post-trauma symptoms, may differ between autistic and non-autistic people[59]. More research into the experience and prevalence of trauma within the autistic population is needed.

---

[52] World Health Organisation - https://www.who.int/health-topics/suicide#tab=tab_1
[53] Hedley, Stokes et al., 2022
[54] World Health Organisation, 2008, 2021
[55] Date et al., 2021 - https://doi.org/10.26181/17082734.v1
[56] Moseley et al., 2021
[57] Ribeiro et al., 2021
[58] Moseley et al., 2021; Pelton et al., 2020a, 2020b
[59] Rumball et al., 2020

Structural issues, such as late diagnosis[60] that delay or prevent access to appropriate supports and interventions throughout critical developmental periods, may contribute to poor mental health and increased suicide risk[61]. Late diagnosis, or failure to correctly identify autism, may disproportionally affect cisgender autistic females who are less likely than cisgender males to receive a diagnosis during childhood[62]. Non-binary or transgender people may also experience barriers or delays in the diagnostic process[63]. Earlier diagnosis and detection of autism, leading to better access to appropriate services, may therefore improve health and wellbeing outcomes and reduce suicide risk[64].

Early diagnosis may potentially help to address this discrepancy by providing earlier access to appropriate supports and interventions

In interviews with autistic women, researchers identified the following system-level barriers to a diagnosis[65]:

- Cost of diagnosis.
- Long wait time and assessment process.
- Assessment tools that lack clarity.
- Diagnostic criteria/tools not based on women or individuals with gender identities outside the gender binary.

Thus, changes to structural barriers to diagnosis are a viable action point to reduce suicide risk for autistic people, particularly autistic women, and people outside the gender binary.

Related to suicide, non-suicidal self-injury (NSSI)[66] is common among autistic people across their lifespan (60%)[67]. NSSI is distinct from suicidal behaviour as it does not include an intent or desire to die[68]; moreover, NSSI may function as a form of emotion regulation or stress management. In people with co-occurring Intellectual Disability (ID) or significant communication challenges, it can be difficult to distinguish NSSI from suicidal behaviour or where harming behaviour occurs with an intent to die. In clinical settings, NSSI is typically considered a high-risk factor for suicidal behaviour in non-autistic populations, yet in the autistic population it may be considered a characteristic of the condition[69]. Thus, there is potential for clinicians to fail to assess for suicidal intent where NSSI is present when diagnostic status is known, or to misdiagnose suicidal behaviour as NSSI. Better

---

[60] Arnold et al., 2019; Richdale et al., 2021
[61] Cassidy et al., 2014
[62] Lockwood Estrin et al., 2021
[63] Hillier et al., 2020; Strang et al., 2018
[64] Mahfouda et al., 2019; Strauss et al., 2021
[65] Murphy et al., 2021
[66] Cha et al., 2018; Nock, 2010
[67] Goldfarb et al., 2021; Moseley et al., 2019; Sahin et al., 2021
[68] The authors acknowledge that NSSI, as distinct from self-harm that include a wish to die (i.e., suicidal intent), can be difficult to determine as suicidal intent is a complex phenomenon, that is furthermore difficult to reliably assess
[69] Cassidy et al., 2018; Moseley et al., 2019; Hedley, Hayward et al., 2022

understanding of NSSI within the autistic population, and of underpinning mechanisms, is critically needed.

> "Suicide and self-harm both arise from that real intolerance – or inability to tolerate difficult or intense emotions. Suicidal or self-harm actions tended to be quite quick and impulsive, but also led to a level of meta-distress, or they were distressing in and of their own right. I have to say this probably isn't exclusive to young autistic people, but possibly more pronounced or harder to process for this (autistic) population."

Professor Jo Robinson, Director of Orygen, Revolution in Mind youth suicide prevention research programs, Conference speaker and Roundtable participant

2.5 What therapy suits which person? Can this be predicted?

Identifying co-occurring mental health difficulties and differentiating autistic suicidality is only the first step in providing supports and care. It is vital that the evidence-base for autism-specific (not simply adapted for use) interventions and supports is expanded to understand what works for whom. Rigorous scientific investigation is therefore needed to identify predictors of both poor and good health and wellbeing outcomes for the individual, and to develop personalised and tailored healthcare intervention and supports. We asked Conference attendees *What do you think should be the next steps and/or priorities for research?*

> "What support autistic people need, what barriers are, what has been helpful"
>
> "Mental health interventions and resources for autistic people"
>
> "Research into what is helpful interventions for autistic individuals who struggle with mental health"
>
> "More research needs to occur with more input from those who have autism."

Respondents of the post-Conference feedback survey

Incorporating the autistic voice is a powerful tool for tailoring interventions to the person. Thus, interventions can shift from generic responses to being specifically relevant and responsive to the individual.

2.6 Universal design

Universal Design refers to the design of an environment to be accessible, understood and used by all people regardless of their culture, age, size, ability, or disability. In this context, universal design should incorporate the basic principles of flexibility, equitable use, effective information communication, the presence of simple and intuitive features, equitable access, low effort, and appropriateness, to create mental health and suicide prevention supports, services and interventions that are accessible for everyone.

If you make changes to the system to better support autistic people, everyone will benefit.

> "The importance of universal design and the sorts of adjustments and considerations that a clinician or a health service might make to make themselves more accessible and appropriate to an autistic person, will generally result in an improved experience for other people who might sit outside the dominant paradigm or presentation of mental illness."

Chris Templin, Amaze Senior Policy Analyst, Policy, Clinical practice and Service Provision Panel moderator and Roundtable co-chair

2.7 Speed of research translation to practice

Translation of research into practice is fundamental. Unfortunately, the implementation of evidence-based intervention and supports is time-consuming, and implementation can be complex.

> "It is a slow process, and it takes us a bit of time to get that across, which is unfortunate, and we need to speed that up"

Professor Robyn Young, Roundtable member, member of the Policy, Clinical Practice and Service Provision Panel

This is frustrating for autistic people and the family, friends, carers, and clinicians supporting them.

> "Research takes a long time to see action and we need action now"

Mel Spencer, mother of two autistic children, CEO, Different Journeys

Thus, researchers must consider the potential impact of their work on the lives of autistic people, and on strategies to ensure that research findings are translated into practice. Strategies must optimise the timeframe from research finding to practice, and research translation needs to be considered as a quantifiable research outcome; researchers therefore cannot assume that publication is the only end goal of a research project. Steps need to be taken to ensure that there is a clear and defined process for ensuring that findings improve the lives of autistic people. To achieve this, researchers need to consider and identify the research priorities of autistic people, and to ensure that autistic people are involved in the development and implementation of new research projects. This may be as researchers, expert consultants, or advisory group members, but must involve autistic people at the commencement of the research process to ensure that aims and goals are firmly aligned with the needs of autistic people. This process must be collaborative with attention paid to sharing and distributing positions of power. In the same way that the important contribution of people with lived experience is beginning to be recognised as essential to conducting effective and relevant research, researchers without applied training or experience should also seek out collaborations with those with the required skillset (e.g., people with applied or clinical skills) to ensure effective translation of research to practice.

In sum, to combat the slow pace of research translation, researchers must be innovative, utilise multiple perspectives, co-design research projects, interventions and supports, and ensure comprehensive community engagement to ensure tools and other outcomes are relevant and useful.

> "Seeing the people who use a system as the experts and the partners in both its design and its implementation"

Chris Templin, Amaze Senior Policy Analyst, Policy, Clinical practice and Service Provision Panel moderator and Roundtable co-chair

Including the autistic experience helps in:

> "Identifying the gaps between mental ill health and access to services and trying to understand what the bridge is between these."

Post-Conference survey respondent

3. Training and Education

Throughout the Conference and Roundtable, the importance of education and training could not be overstated. There is a lack of knowledge and understanding of autism by professionals and the wider community of what mental ill health and suicidality look like for autistic people, which may differ from other priority populations[70]. Professionals need to develop effective communication strategies with autistic people and confidence in their approach to working with autistic clients, including knowledge concerning the selection of appropriate interventions and supports.

Moreover, the wider community (e.g., government, health professionals, educators, and the broader health sector) need education and training to help them better understand autism, including *what it is like to live as an autistic person*. A program of education and training in cultural humility should help to foster an attitude of curiosity about the personal experience of autism that is often neglected in formal training and education.

The number of attendees at the Conference (620 users registered on the Conference site, internationally) indicates professional and community interest in learning more about autism, mental health, and suicide prevention. Indeed, many professionals have expressed a strong desire for training in autism, and how to work effectively with autistic people.

> "What we are seeing is that enthusiasm from clinicians to want to learn and to want to better understand"

Professor Sandra Radovini, the Policy, Clinical Practice and Service Provision Panel member

---

[70] Jager-Hyman et al., 2020

We asked Conference attendees "*Do you think the information presented at the Conference will influence the way you interact with autistic people?*"

> "Yes absolutely. The resources and language shared will positively influence my interactions"
>
> "Definitely. Particularly the advice around matching their communication style and allowing time to respond"
>
> "I think it reinforced a lot of what I already do"

Allied health respondents to the post-Conference survey

Our autistic contributors at the Conference and Roundtable spoke about many instances where they felt their voices were ignored, they were treated without respect or 'othered' by support professionals and the wider community (for an example listen to our guest speaker Lisa Morgan discuss her experiences here - https://suicideprevention-22d81.web.app). This disregarding of an autistic person's autonomy was a prevalent narrative that the Roundtable members indicated requires urgent attention.

All education and training programs should be of universal design. This approach is the most likely to lead to benefits for anyone seeking supports for mental ill health and suicidality.

> “Training the broader mental health sector in how better to serve autistic people should translate to better services for everyone, for every client within a service”

Dr Darren Hedley, OTARC Health and Wellbeing Program Leader, Conference chair and Roundtable co-chair

> “The sort of training that people need to work with somebody who is autistic or otherwise neurodivergent would be so useful for anyone who accesses a health service. So, for someone who is in distress, being slow and listening and taking time and seeing the perspective of that person along with many other things that have been raised today, would be useful for anybody accessing the service.”

Eileesh Diviney, manager of suicide prevention programs in the Department of Health in Victoria, Policy, Clinical Practice and Service Provision Panel member

The following sections discuss areas of training considered by Conference attendees and members of the Roundtable. The training recommendations focus on clinical-level training. We also note the importance of gatekeeper training and refer to the Suicide Response Project (www.suicideresponseproject.com), which provides general population training with specific autism content, co-developed with autistic people.

3.1 Universal cultural humility and competence training

Above, we outlined the importance of the autistic culture and experience in tackling stigma, discrimination, and the reduction of barriers to services that would be helpful for autistic people seeking assistance for mental ill health or suicidality. In particular, 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. This can be implemented in multiple ways. For example:

- Incorporated into early childhood education educator training and classroom fundamentals.
- Incorporated into personal development, health, and physical education curriculum as a population of interest.
- Compulsory cultural humility professional development training of all care workers and educators to be required under their registration.

Training should be grounded in an underlying aim of fostering a curiosity of experience, an openness to learning and mutual respect while creating a climate of genuine cultural humility across systems, starting with care professionals, support organisations, teaching, educators, providers, and leadership. Once cultural humility is embedded in experiences of, and interactions with, wider systems, it not only allows role modelling and incidental opportunities for educating others in cultural humility, but also potentially creates safer and more accessible environments for autistic individuals, teachers, and professionals.

Conference guest speaker Lisa Morgan suggested that a universal set of Client's Rights for autistic people could be presented by a professional at their first meeting with their client.

> "For example, the right to not make eye contact, the right to present differently than you feel inside..."

Lisa Morgan, suicide prevention expert, autistic author, Conference guest speaker and Roundtable participant

This would make talking about individual masking behaviours much easier during the first meeting, enabling the professional to establish open communication, directed by the client, and reducing the risk to the relationship.

> "I think that would help start the conversation about masking right from the start of a therapeutic encounter, which could be very beneficial!"

Dr Brenna Maddox, University of North Carolina-Chapel Hill, USA, Conference guest speaker and Roundtable participant

It also allows the professional to be reflective in the interaction, acknowledging their own inherent biases towards non-autistic thought and experience.

3.2 Mental wellbeing assessment tools

It is important then that any measurement tools used in autistic populations are 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. This requires that instruments are not only psychometrically validated in autistic populations but are developed and designed specifically for use by autistic people. Autistic people need to contribute to this process following accepted guidelines for co-development and co-design. As one example, current measurement of quality of life may not consider wellbeing indications specific to autistic people, such as[71]:

- Access to focused interests.
- Sensory needs.

---

[71] Martinelli, 2021

- Relationship to autistic identity.

Currently, only one suicide risk assessment instrument, the Suicidal Behaviors Questionnaire, Autism Spectrum Conditions (SBQ-ASC[72]), has been specifically developed for use by autistic people. However, the measure is designed for research purposes and has not been validated for clinical use. Two new suicide assessment tools have been developed for use by autistic people in clinical settings, and are currently undergoing peer-review[73]. The tools are modified from existing instruments and were developed with autistic people and those with lived experience of autism and suicide behaviour.

3.3 Allied health professional training and ongoing registration

Autism-specific education and training must be incorporated into the regulatory structure of professions offering mental health and suicide prevention services. The need for training options was identified and supported by mental health sector professionals who participated in the Conference Panels and at the Roundtable, and it is clear there is a demand for appropriate and specialist training for the sector. Globally, there is a lack of widespread, accessible, and available training in mental health, suicide prevention and autism.

The Roundtable calls for the provision of widespread professional training, with incorporation of specialist modules integrated into university-level courses and throughout professional internship and other professional training programmes.

---

[72] Cassidy et al., 2021

[73] The Suicidal Ideation Attributes Scale-Modified (SIDAS-M) is a 5-item assessment of recent suicidal ideation, currently under review: Hedley, Batterman et al., 2022. The Suicide Assessment Kit Suicide Risk Screener-Modified (SAKSRS-M) is an 11-item clinically administered screening tool for assessing suicide risk and behaviour that is being prepared for submission for peer review.

3.4 Mental health sector responsibility

One important consideration by the Roundtable was the reluctance of the mental health sector to acknowledge responsibility for the mental health and wellbeing of the autistic population. Instead, autistic people and responsibility for their mental health needs are considered the responsibility of the disability sector. In addition, it was noted that autism is too often considered a condition of childhood, with little appreciation for the fact that autistic children eventually develop into autistic adults. It was noted that searches of mental health sector websites failed to provide any hits when "autism" was entered as a search term. The disability sector, however, considers mental health to be out of scope, and disability service providers do not have specialist training in mental health to serve the mental health needs of autistic people. This diffusion of responsibility results in a failure to meet the mental health needs of the autistic population, and so autistic people find themselves unable to connect with trained or knowledgeable providers. What is needed is for these sectors to work together, and for the mental health sector to begin to view the mental health and wellbeing of autistic people as being part of their 'core business'. To date, training of the adult mental health sector has been sporadic or isolated to individual pilot programs (e.g., Monash Health). A nationwide, coordinated effort is needed to address this shortfall.

3.5 Identifying mental ill health and crisis in autistic people

Lived experience experts tell us that the warning signs[74] and signs of distress are different for autistic people.

> “Our distress does not look the way that people expect it to look. And that can then impact our access to help. I have certainly found myself in positions where, I have been very distressed, very much at crisis point and in need of immediate help.
>
> But my presentation during those times is essentially much more neurotypical. I become still and quiet and I appear very calm…. So, I can say, "I am in crisis. I need help now." But I look like a non-autistic person who is perfectly calm. That has meant I have had experiences where professionals have not taken any action, even though I am telling them I am in crisis.”

Dr Jac Den Houting, autistic academic, Lived Experience Panel member and Roundtable participant

---

[74] Morgan et al., 2021

There is a clear need for education and training of frontline professionals to develop confidence in working with neurodivergent people in general but particularly in the differing presentations of distress and crisis and the overlap of autism and mental ill health.

> “There is not enough knowledge about suicide being different in autism but there is even not enough knowledge about suicidal behaviours in the education sector and in training”

Prof Kairi Kõlves, suicide prevention expert, and Roundtable participant

Lack of knowledge about autism and the co-occurrence of mental health conditions and autism may lead to autistic people who are in crisis and seeking assistance being turned away from services.

> “They (autistic people) actually do present in hospitals, when I have rung ambulances forpeople and got them into services, when they get there, and someone brought this up in an earlier session today, about camouflaging, present quite well. I have had to seriously be on the phone and advocate and say “yes, they are going to present well, they are an autistic person. They are camouflaging the condition”. But I have serious concerns about this person to be able to get them to get the help, otherwise, and this has occurred several times within an hour or two, they have simply been released. That is despite the fact that I think that they are suicidal at the time.”

Professor Robyn Young, clinical psychologist, Roundtable member, member of the Policy, Clinical Practice and Service Provision Panel

3.6 Nurturing autistic professionals and researchers

Autistic researchers face additional obstacles to participating in the research process, compared to non-autistic researchers. A recent literature review of works written by autistic researchers found two themes[75]:

1. A deficit-based autism narrative.
2. Structural barriers.

---

[75] Mckeown, 2021

The following adjustments may make the research experience more accessible to autistic researchers[76]:

- Non-autistic researchers take time to formally reflect on their biases.
- Assess language use.
- Learn about the autistic experience.
- Embrace neurodiversity.
- Be an ally to autistic colleagues.

Embracing autistic self-regulation strategies, such as stimming and wearing headphones and sunglasses, may promote health and wellbeing, within the workplace and other settings (e.g., higher education)[77].

Within the mental health sector, autistic clinicians may be a valuable resource for autistic people seeking supports. A searchable portal was suggested to help autistic people find autistic clinicians.

Attracting autistic clinicians to university and other education settings can be done in several ways:

- Targeted scholarships. For example, La Trobe University offers the Sylvia Walton Honours Scholarship, which supports an autistic psychology student undertaking their Honours year within the Olga Tennison Autism Research Centre[78].
- Structuring courses to support autistic students. For example, applying universal design principles of flexibility, equity, and accessibility to the design of the course to improve retention including co-design and co-development.
- Ensuring higher education institutions have a support system in place for autistic and otherwise neurodivergent students (e.g., mentor/buddy system).

---

[76] Mckeown, 2021
[77] Cobbaert et al., 2021
[78] La Trobe University - https://www.latrobe.edu.au/scholarships/sylvia-walton-honours-scholarship

Acknowledgements

We would like to offer special thanks to Mr Steve Dimopoulous, Parliamentary Secretary for Mental Health and Parliamentary Secretary to the Premier, Victoria and his office for their support for the ASfAR Conference and for contributing the foreword of this report.

ASfAR Conference Organising Committee

Perrin Date
Melinda Denham
Dr Melissa Gilbert
Dr Elfriede Ihsen
Alex Haschek
David Murphy
Dr Darren Hedley
Margaret Laughton
Professor Alison Lane
Michael Leahy
Radhika Nair

Funding

The Roundtable and writing of this report were supported by funding from the Australasian Society for Autism Research (ASfAR) and the conference sponsors. Darren Hedley is supported by a Suicide Prevention Australia National Suicide Prevention Research Fellowship. Jo Robinson is funded by a National Health and Medical Research Council (NHMRC) Investigator Grant (GNT2008460) and a University of Melbourne Dame Kate Campbell Fellowship. The authors declare no actual or potential conflict of interest.

Conference Sponsors

untapped.

amaze
Shaping the future for Autism.

different journeys
Empowering Autism

The Suicide Response Project

auticon

The Emotions Clinic
AUSTRALIA

AutismCRC

autism spectrum
AUSTRALIA

References

Andrews, H., Hedley, D., & Bury, S. (2021, December 9). *Self-determination as a mediator between autism traits and quality of life* [Conference presentation]. Australasian Society for Autism Research, Melbourne, VIC, Australia.

Arnold, S., Foley, K., Hwang, Y. I., Richdale, A. L., Uljarevic, M., Lawson, L. P., Cai, R. Y., Falkmer, T., Falkmer, M., Lennox, N. G., Urbanowicz, A., Trollor, J. (2019). Cohort profile: The Australian Longitudinal Study of Adults with Autism (ALSAA). *BMJ Open, 9*(12). e030798. http://dx.doi.org/10.1136/bmjopen-2019-030798

Arwert, T. G., & Sizoo, B. B. (2020). Self-reported suicidality in male and female adults with autism spectrum disorders: Rumination and self-esteem. *Journal of Autism & Developmental Disorders, 50*(10), 3598-3605. https://doi.org/10.1007/s10803-020-04372-z

Department of Health. (2020). *National suicide prevention adviser: Final advice.* https://www.health.gov.au/resources/publications/national-suicide-prevention-adviser-final-advice

Australian Institute of Health and Welfare. (2022). *Mental health services in Australia* [Web report]. https://www.aihw.gov.au/reports/mental-health-services/mental-health-services-in-australia/report-contents/mental-health-workforce

Benn, R., Flower, R., & Jellett, R. (2021, December 9). *The experiences of autistic adults working with psychologists in Australia* [Conference presentation]. Australasian Society for Autism Research, Melbourne, VIC, Australia.

Botha, M. (2021). Academic, activist, or advocate? Angry, entangled, and emerging: A critical reflection on autism knowledge production. *Frontiers in Psychology*, *12*, 727542–727542. https://doi.org/10.3389/fpsyg.2021.727542

Botha, M., & Frost, D. M. (2020). Extending the minority stress model to understand mental health problems experienced by the autistic population. *Society & Mental Health, 10*(1), 20–34. https://doi.org/10.1177/2156869318804297

Brown, C. M., Hedley, D., Fuller-Tyszkiewicz, M., Hooley, M., & Stokes, M. A. (2021, December 9). *Personal wellbeing and stress in autistic adults: Before and during COVID-19* [Conference presentation]. Australasian Society for Autism Research, Melbourne, VIC, Australia.

Bryan, C. J., Butner, J. E., May, A. M., Rugo, K. F., Harris, J. A., Oakey, D. N., ... & Bryan, A. O. (2020). Nonlinear change processes and the emergence of suicidal behavior: A conceptual model based on the fluid vulnerability theory of suicide. *New Ideas in Psychology*, *57*, 100758-100767. https://doi.org/10.1016/j.newideapsych.2019.100758

Bulluss, E. (2021). *Therapist cultural humility is a crucial component of psychotherapy with autistic clients*. https://www.samsonandbulluss.com/application/files/7716/3842/1332/CulturalHumilitySoP_December_2021_pp4650-ErinBulluss.pdf

Bury, S. M., Hayward, S. M., Dissanayake, C., & Hedley, D. (2021, December 9). *Utilising lived experience and co-design to develop autism specific workplace mental health training* [Conference presentation]. Australasian Society for Autism Research, Melbourne, VIC, Australia.

Bury, S. M., Jellett, R., Spoor, J. R., & Hedley, D. (2020). "It defines who I am" or "It's something I have": What language do [autistic] Australian adults [on the autism spectrum] prefer? *Journal of Autism & Developmental Disorders*. Advance online publication. https://doi.org/10.1007/s10803-020-04425-3

Cassidy, S. A., Bradley, L., Cogger-Ward, H. & Rodgers, J. (2021). Development and validation of the suicidal behaviours questionnaire: Autism spectrum conditions in a community sample of autistic, possibly autistic and non-autistic adults. *Molecular Autism 12*(1), 1-46. https://doi.org/10.1186/s13229-021-00449-3

Cassidy, S. A., Bradley, P., Robinson, J., Allison, C., McHugh, M., & Baron-Cohen, S. (2014). Suicidal ideation and suicide plans or attempts in adults with Asperger's syndrome attending a specialist diagnostic clinic: A clinical cohort study. *Lancet Psychiatry, 1*(2), 142-147. https://doi.org/10.1016/S2215-0366(14)70248-2

Cassidy, S. A., Bradley, L., Shaw, R., & Baron-Cohen, S. (2018). Risk markers for suicidality in autistic adults. *Molecular Autism*, *9*(1), 1-14. https://doi.org/10.1186/s13229-018-0226-4

Cassidy, S. A., Gould, K., Townsend, E., Pelton, M., Robertson, A. E., & Rodgers, J. (2020). Is camouflaging autistic traits associated with suicidal thoughts and behaviours? Expanding the interpersonal psychological theory of suicide in an undergraduate student sample. *Journal of Autism & Developmental Disorders*, *50*(10), 3638-3648. https://doi.org/10.1007/s10803-019-04323-3

Cha, C. B., Franz, P. J., M. Guzmán, E., Glenn, C. R., Kleiman, E. M., & Nock, M. K. (2018). Annual research review: Suicide among youth–epidemiology, (potential) etiology, and treatment. *Journal of Child Psychology & Psychiatry*, *59*(4), 460-482. https://doi.org/10.1111/jcpp.12831

Cobbaert, L., Minkov, R., & Sellen, M. (2021, December 9). *Sensory processing: From autism to mental health* [Conference presentation]. Australasian Society for Autism Research, Melbourne, VIC, Australia.

Conner, C. M., Golt, J., Righi, G., Shaffer, R., Siegel, M., & Mazefsky, C. A. (2020). A comparative study of suicidality and its association with emotion regulation impairment in large ASD and US census-matched samples. *Journal of Autism & Developmental Disorders*, *50*(10), 3545-3560. https://doi.org/10.1007/s10803-020-04370-1

Cooke, K., Ridgway, K., Westrupp, E., Hedley, D., Hooley, M., & Stokes, M. A. (2021, December 9). *Interpersonal violence in autism: Prevalence, risk factors, and outcomes of victimisation* [Conference presentation]. Australasian Society for Autism Research, Melbourne, VIC, Australia.

Costa, A. P., Loor, C., & Steffgen, G. (2020). Suicidality in adults with autism spectrum disorder: The role of depressive symptomatology, alexithymia, and antidepressants. *Journal of Autism & Developmental Disorders*, *50*(10), 3585-3597. https://doi.org/10.1007/s10803-020-04433-3

Date, P., Denham, M., Gilbert, M., Ihsen, E., Haschek, A., Hedley, D., Lane, A., Laughton, M., Leahy, M., Murphy, D., & Nair, R. (2021, December 9). *Health, Wellbeing and Suicide Prevention in Autism: Bringing autistic people, researchers and health professionals together state-based conference: Abstracts and transcripts* [Conference contribution]. Australasian Society for Autism Research, Melbourne, VIC, Australia. https://doi.org/10.26181/17082734.v1

De Leo, D., Goodfellow, B., Silverman, M., Berman, A., Mann, J., Arensman, E., Hawton, K., Phillips, M. R., Vijayakumar, L., Andriessen, K., Chavez-Hernandez, A. M., Heisel, M., & Kõlves, K. (2021). International study of definitions of English-language terms for suicidal behaviours: A survey exploring preferred terminology. *BMJ Open*, *11*(2), e043409. https://doi.org/10.1136/bmjopen-2020-043409

Denney, K., Stokes, M. A., Hayward, S. M., Nicholas, D., Clapperton, A., Dissanayake, C., Robinson, J., Trollor, J., Uljarević, M., & Hedley, D. (2021, December 9). *Exploring autistic people's perspectives on their use of, and barriers to mental healthcare access and services in Australia* [Conference presentation]. Australasian Society for Autism Research, Melbourne, VIC, Australia.

Dietz, P. M., Rose, C. E., McArthur, D., & Maenner, M. (2020). National and state estimates of adults with autism spectrum disorder. *Journal of Autism & Developmental Disorders, 50*(12), 4258–4266. https://doi.org/10.1007/s10803-020-04494-4

Dow, D., Morgan, L., Hooker, J. L., Michaels, M. S., Joiner, T. E., Woods, J., & Wetherby, A. M. (2021). Anxiety, depression, and the interpersonal theory of suicide in a community sample of adults with autism spectrum disorder. *Archives of Suicide Research*, *25*(2), 297-314. https://doi.org/10.1080/13811118.2019.1678537

Finn, M., Flower, R., & Hedley, D. A (2021, December 9). *Qualitative Exploration of the Impact of Camouflaging Behavior on the Mental Health and Wellbeing of Autistic People, Experienced During a Job Interview*[Conference presentation]. Australasian Society for Autism Research, Melbourne, VIC, Australia.

Flower, R. L., Dickens, L. M. & Hedley, D. (2021). Barriers to Employment: Raters' Perceptions of Male Autistic and Non-Autistic Candidates During a Simulated Job Interview and the Impact of Diagnostic Disclosure. *Autism in Adulthood, 3*(4). https://doi.org/10.1089/aut.2020.0075

George, R., & Stokes, M. A. (2018a). Sexual orientation in autism spectrum disorder. *Autism Research*, *11*(1), 133-141. https://doi.org/10.1002/aur.1892

George, R., & Stokes, M. A. (2018b). A quantitative analysis of mental health among sexual and gender minority groups in ASD. *Journal of Autism & Developmental Disorders*, *48*(6), 2052–2063. https://doi.org/10.1007/s10803-018-3469-1

Goldfarb, Y., Zafrani, O., Hedley, D., Yaari, M., & Gal, E. (2021). Autistic adults' subjective experiences of hoarding and self-injurious behaviors. *Autism. 25*(5), 1457-1468. https://doi.org/10.1177/1362361321992640

Goodfellow, B., Kõlves, K., & De Leo, D. (2019). Contemporary definitions of suicidal behavior: A systematic literature review. *Suicide & Life-threatening Behavior*, *49*(2), 488–504. https://doi.org/10.1111/sltb.12457

Hand, B. N., Benevides, T. W., & Carretta, H. J. (2020). Suicidal ideation and self-inflicted injury in Medicare enrolled autistic adults with and without co-occurring intellectual disability. *Journal of Autism & Developmental Disorders*, *50*(10), 3489-3495. https://doi.org/10.1007/s10803-019-04345-x

Hedley, D., Batterham, P., Deady, M., Uljarevic, M., Bury, S., Clapperton, A., Robinson, J., Trollor, J., & Stokes, M. (2022, August 24-27). *Development and validation of two new scales for assessing suicide risk and behavior in autism* [Symposium] European Symposium for Suicide and Suicidal Behaviour (ESSSB) 19th Conference, Copenhagen, Denmark.

Hedley, D., Hayward, S. M., Clarke, A., Stokes, M., & Uljarević, M. (2022). Suicide and autism: A lifespan perspective. In R. Stancliffe, M. Y. Wiese, P. McCallion, & M. McCarron (Eds.), *End of life and people with intellectual and developmental disability: Contemporary issues, challenges, experiences and practice.* Palgrave Macmillan.

Hedley, D., Stokes, M. A., & Trollor, J. (2022). Suicide by young Australians, 2006-2015; A cross-sectional analysis of national coronial data [Letter to the editor]. *Medical Journal of Australia, 216*(1). https://doi.org/10.5694/mja2.51359

Hedley, D., & Uljarević, M. (2018). Systematic review of suicide in autism spectrum disorder: Current trends and implications. *Current Developmental Disorders Reports, 5*, 65-76. https://doi.org/10.1007/s40474-018-0133-6

Hedley, D., Uljarević, M., Cai, R-Y., Bury, S. M., Stokes, M. A., & Evans, D. W. (2021). Domains of the autism spectrum disorder phenotype, cognitive control, and rumination as transdiagnostic predictors of DSM-5 suicide risk. *PLoS ONE, 16*(1), e0245562. https://doi.org/10.1371/journal.pone.0245562

Hedley, D., Uljarević, M., Foley, K-R., Richdale, A., & Trollor, J. (2018). Risk and protective factors underlying suicidal ideation in autism spectrum disorder. *Depression & Anxiety, 35,* 648-657. https://doi.org/10.1002/da.22759

Hill, K., Chan, C., Murphy, D., Barbaro, J., & Hedley, D. (2021, December 9). *Co-design of a community-based autism and LGBTIQA+ inclusive suicide prevention education tool* [Conference presentation]. Australasian Society for Autism Research, Melbourne, VIC, Australia.

Hill, N. T. M., Witt, K., Rajaram, G., McGorry, P. D., & Robinson, J. (2021). Suicide by young Australians, 2006–2015: A cross-sectional analysis of national coronial data. *Medical Journal of Australia*, *214*, 133–139. https://doi.ord/10.5694/mja2.50876

Hillier, A., Gallop, N., Mendes, E., Tellez, D., Buckingham, A., Nizami, A., & O'Toole, D. (2020). LGBTQ+ and autism spectrum disorder: Experiences and challenges. *International Journal of Transgender Health*, *21*(1), 98-110. https://doi.org/10.1080/15532739.2019.1594484

Hirvikoski, T., Boman, M., Chen, Q., D'Onofrio, B. M., Mittendorfer-Rutz, E., Lichtenstein, P., ... & Larsson, H. (2020). Individual risk and familial liability for suicide attempt and suicide in autism: A population-based study. *Psychological Medicine*, *50*(9), 1463-1474. https://doi.org/10.1017/S0033291719001405

Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P., & Bölte, S. (2016). Premature mortality in autism spectrum disorder. *British Journal of Psychiatry, 208*, 232-238. https://doi.org/10.1192/bjp.bp.114.160192

Holden, R., Mueller, J., McGowan, J., Sanyal, J., Kikoler, M., Simonoff, E., Velupillai, S., & Downs, J. (2020). Investigating bullying as a predictor of suicidality in a clinical sample of adolescents with autism spectrum disorder. *Autism Research, 13*(6), 988–997. https://doi.org/10.1002/aur.2292

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, 94*(4)1-14. https://doi.org/10.1017/S0033291718002283

Hosozawa, M., Sacker, A., & Cable, N. (2021). Timing of diagnosis, depression and self-harm in adolescents with autism spectrum disorder. *Autism*, *25*(1), 70-78. https://doi.org/10.1177/1362361320945540

Huang, Y., Arnold, S. R., Foley, K. R., Lawson, L. P., Richdale, A. L., & Trollor, J. N. (2021). Factors associated with age at autism diagnosis in a community sample of Australian adults. *Autism Research*, *14*(12), 2677-2687. https://doi.org/10.1177/1362361320945540

Jager-Hyman, S., Maddox, B. B., Crabbe, S. R., & Mandell, D. S. (2020). Mental Health Clinicians' Screening and Intervention Practices to Reduce Suicide Risk in Autistic Adolescents and Adults. *Journal of autism and developmental disorders*, *50*(10), 3450–3461. https://doi.org/10.1007/s10803-020-04441-3

Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism, 20*(4), 442–462. https://doi.org/10.1177/1362361315588200

Kent, R., & Simonoff, E. (2017). Prevalence of anxiety in autism spectrum disorders. In C. M. Kerns, P. Renno, E. A. Storch, P. C. Kendall, & J. J. Wood (Eds.), *Anxiety in children and adolescents with autism spectrum disorder: Evidence-based assessment and treatment* (pp. 5-32). Elsevier Inc.

Kirby, A. V., Bakian, A. V., Zhang, Y., Bilder, D. A., Keeshin, B. R., & Coon, H. (2019). A 20-year study of suicide death in a state-wide autism population. *Autism Research, 12*, 658-666. https://doi.org/10.1002/aur.2076

Klomek, A. B., Sourander, A., & Gould, M. S. (2011). Bullying and suicide. *Psychiatric Times, 28*(2), 27-32. https://www.psychiatrictimes.com/view/bullying-and-suicide

Klonsky, E. D., Saffer, B. Y., & Bryan, C. J. (2018). Ideation-to-action theories of suicide: A conceptual and empirical update. *Current Opinion in Psychology*, *22*, 38-43. https://doi.org/10.1016/j.copsyc.2017.07.020

Kõlves, K., Fitzgerald, C., Nordentoft, M., Wood, S. J., & Erlangsen, A. (2021). Assessment of Suicidal Behaviors Among Individuals With Autism Spectrum Disorder in Denmark. *JAMA network open*, *4*(1), e2033565. https://doi.org/10.1001/jamanetworkopen.2020.33565

La Trobe University. (n.d.). *Sylvia Walton honours scholarship.* https://www.latrobe.edu.au/scholarships/sylvia-walton-honours-scholarship

Lilley, R., Lawson, W., Hall, G., Mahony, J., Clapham, H., Heyworth, M., ... & Pellicano, E. (2021). 'A way to be me': Autobiographical reflections of autistic adults diagnosed in mid-to-late adulthood. *Autism*, *26*(2), 1-14. https://doi.org/10.1177/13623613211050694

Lockwood Estrin, G., Milner, V., Spain, D., Happé, F., & Colvert, E. (2021). Barriers to autism spectrum disorder diagnosis for young women and girls: A systematic review. *Review Journal of Autism & Developmental Disorders*, *8*(4), 454-470. https://doi.org/10.1007/s40489-020-00225-8

Lory, B. (2019). For the love of science? *Autism in Adulthood, 1*(1), 12-14. https://doi.org/10.1089/aut.2018.0005

Mahfouda, S., Panos, C., Whitehouse, A. J., Thomas, C. S., Maybery, M., Strauss, P., ... & Lin, A. (2019). Mental health correlates of autism spectrum disorder in gender diverse young people: Evidence from a specialised child and adolescent gender clinic in Australia. *Journal of Clinical Medicine*, *8*(10), 1503-1517. https://doi.org/10.3390/jcm8101503

Mandy, W., Midouhas, E., Hosozawa, M., Cable, N., Sacker, A., & Flouri, E. (2022). Mental health and social difficulties of late-diagnosed children with autism, across childhood and adolescence. *The Journal of Child Psychology & Psychiatry,* Advance online publication. https://doi.org/10.1111/jcpp.13587

Mantzalas, J., Richdale, A. L., Adikari, A., Lowe, J., Dissanayake, C. (2021) What is autistic burnout? A thematic analysis of posts on two online platforms. *Autism in Adulthood*. https://doi.org/10.1089/aut.2021.0021

Martinelli, M. (2021, December 9). *Autistic wellbeing and how it can be supported: Can we really homogenise a heterogeneous, non-homogeneous group and expect good wellbeing outcomes?* [Conference presentation]. Australasian Society for Autism Research, Melbourne, VIC, Australia.

Mckeown, G. (2021, December 9). *Supporting autistic autism researchers through the detrimental impacts of autism research* [Conference presentation]. Australasian Society for Autism Research, Melbourne, VIC, Australia.

McQuaid, G. A., Lee, N. R., & Wallace, G. L. (2021). Camouflaging in autism spectrum disorder: Examining the roles of sex, gender identity, and diagnostic timing. *Autism*, *26*(2), 552-559. https://doi.org/10.1177/13623613211042131

Mesibov, G. B., Shea, V., Schopler, E., Adams, L., Merkler, E., Burgess, S., Mosconi, M. S., Chapman. M., Tanner, C., & Van Bourgondien, M. E. (2004) *The culture of autism*. In G. B. Mesibov, V. Shea, & E. Schopler (Eds.), *The Teacch approach to autism spectrum disorders.* Springer. https://doi.org/10.1007/978-0-306-48647-0_3

Morgan, L. (2021). *Autism crisis support by a board-certified autism specialist.* https://autism-crisis-support.com

Morgan, L., Cassidy, S., Donahue, M., Maddox, B., Benevides, T., & Pelton, M. (2021). Warning Signs of Suicide for Autistic People: An autism-specific resource based on research findings and expert consensus. https://autismandsuicide.wpcomstaging.com/wp-content/uploads/2021/10/Warning-Signs-Resource-Sept-2021.pdf

Moseley, R. L., Gregory, N. J., Smith, P., Allison, C., & Baron-Cohen, S. J. M. A. (2019). A ‘choice’, an ‘addiction’, a way ‘out of the lost’: Exploring self-injury in autistic people without intellectual disability. *Molecular Autism*, *10*(1), 1-23. https://doi.org/10.1186/s13229-019-0267-3

Moseley, R. L., Gregory, N. J., Smith, P., Allison, C., Cassidy, S., & Baron-Cohen, S. (2021, December 9). *Exploring the relevance of the interpersonal theory of suicide in autistic people* [Conference presentation]. Australasian Society for Autism Research, Melbourne, VIC, Australia.

Moseley, R. L., Gregory, N. J., Smith, P., Allison, C., Cassidy, S., & Baron-Cohen, S. (in press). The relevance of the interpersonal theory of suicide for predicting past-year and lifetime suicidality in autistic adults. *Molecular Autism.*

Muniandy, M., Richdale, A., & Lawson, L. (2021, December 9). *Stress and wellbeing in autistic adults: Exploring the moderating role of coping* [Conference presentation]. Australasian Society for Autism Research, Melbourne, VIC, Australia.

Murphy, S. K., Flower, R., & Jellett, R. (2021, December 9). *Women seeking an autism diagnosis in Australia: What helps and what hinders?* [Conference presentation]. Australasian Society for Autism Research, Melbourne, VIC, Australia.

Murray, C., Kovshoff, H., Brown, A., Abbott, P., & Hadwin, J. A. (2019). Exploring the anxiety and depression profile in individuals diagnosed with an autism spectrum disorder in adulthood. *Research in Autism Spectrum Disorders*, *58*, 1–8. https://doi.org/S1750946718301612

Nock, M. K. (2010). Self-injury. *Annual Review of Clinical Psychology*, *6*(1), 339-363. https://doi.org/10.1146/annurev.clinpsy.121208.131258

O'Connor, R. C., & Kirtley, O. J. (2018). The integrated motivational–volitional model of suicidal behaviour. *Philosophical Transactions of the Royal Society*, *373*(1754), 1–10. https://doi.org/10.1098/rstb.2017.0268

Oxford Reference. (n.d.). *Overview: Culture.* https://www.oxfordreference.com/view/10.1093/oi/authority.20110901080526139

Paquette-Smith, M., Weiss, J., & Lunsky, Y. (2014). History of suicide attempts in adults with Asperger syndrome. *Crisis, 35(4),* 273–277. https://doi.org/10.1027/0227-5910/a000263

Pellicano, E., Brett, S., den Houting, J., Heyworth, M., Magiati, I., Steward, R., Urbanowicz, A., & Stears, M. (2021). COVID-19, social isolation and the mental health of autistic people and their families: A qualitative study. *Autism*. Advance online publication. https://doi.org/10.1177/13623613211035936

Pelton, M. K., Crawford, H., Robertson, A. E., Rodgers, J., Baron-Cohen, S., & Cassidy, S. (2020a). Understanding suicide risk in autistic adults: Comparing the Interpersonal Theory of Suicide in autistic and non-autistic samples. *Journal of Autism & Developmental Disorders*, *50*(10), 3620-3637. https://doi.org/10.1007/s10803-020-04393-8

Pelton, M. K., Crawford, H., Robertson, A. E., Rodgers, J., Baron-Cohen, S., & Cassidy, S. (2020b). A measurement invariance analysis of the Interpersonal Needs Questionnaire and Acquired Capability for Suicide Scale in autistic and non-autistic adults. *Autism in Adulthood*, *2*(3), 193-203. https://doi.org/10.1089/aut.2019.0055

Raymaker, D. M., Teo, A. R., Steckler, N. A., Lentz, B., Scharer, M., Delos Santos, A., Kapp, S. K., Hunter, M., Joyce, A., & Nicolaidis, C. (2020). "Having all of your internal resources exhausted beyond measure and being left with no clean-up crew": Defining autistic burnout. *Autism in Adulthood*, *2*(2), 132–143. https://doi.org/10.1089/aut.2019.0079

Ribeiro, J. D., Linthicum, K. P., Harris, L. M., Bryen, C. P., & Broshek, C. E. (2021). Raising doubt about the anticipated consequences of suicidal behavior: Evidence for a new approach from laboratory and real-world experiments. *Behaviour Research & Therapy*, *147*, 103971-103971. https://doi.org/10.1016/j.brat.2021.103971

Richards, G., Kenny, R., Griffiths, S., Allison, C., Mosse, D., Holt, R., O'Connor, R. C., Cassidy, S., & Baron-Cohen, S. (2019). Autistic traits in adults who have attempted suicide. *Molecular Autism, 10*(1), 1-10. https://doi.org/10.1186/s13229-019-0274-4

Richdale, A. L., Hedley, D., Haschek, A., Chetcuti, L., Radovini, A., Saunders, F., Ball, R., Bury, S., Mantzalas, J., Fisher, C. A., Stokes, M., Lawson, L. P., & Morris, E. (2021). *La Trobe University Olga Tennison Autism Research Centre (OTARC) response to the Select Committee on Mental Health and Suicide Prevention.* La Trobe University. https://doi.org/10.26181/605914d9aabe4

Rumball, F., Happé, F., & Grey, N. (2020). Experience of trauma and PTSD symptoms in autistic adults: Risk of PTSD development following DSM-5 and non-DSM-5 traumatic life events. *Autism Research*, *13*(12), 2122-2132. https://doi.org/10.1002/aur.2306

Sahin, E., Denney, K., Turner, K., Sanguino, H., Bury, S. M., Uljarević, M., Clapperton, A., Dissanayake, C., Robinson, J., Trollor, J., Stokes, M. A., McMorris, C., & Hedley, D. (2021, December 9). *Suicidal behaviour in Australian and Canadian children, adolescents, and adults on the autism spectrum* [Conference presentation]. Australasian Society for Autism Research, Melbourne, VIC, Australia.

Santomauro, D. F., Hedley, D., Sahin, E., Ferrari, A. J., & Stokes, M. A. (2021, December 9). *The global burden of suicide among people on the autism spectrum* [Conference presentation]. Australasian Society for Autism Research, Melbourne, VIC, Australia.

South, M., Beck, J. S., Lundwall, R., Christensen, M., Cutrer, E. A., Gabrielsen, T. P., ... & Lundwall, R. A. (2020). Unrelenting depression and suicidality in women with autistic traits. *Journal of Autism & Developmental Disorders*, *50*(10), 3606-3619. https://doi.org/10.1007/s10803-019-04324-2

Strang, J. F., Powers, M. D., Knauss, M., Sibarium, E., Leibowitz, S. F., Kenworthy, L., ... & Anthony, L. G. (2018). "They thought it was an obsession": Trajectories and perspectives of autistic transgender and gender-diverse adolescents. *Journal of Autism & Developmental Disorders*, *48*(12), 4039-4055. https://doi.org/10.1007/s10803-018-3723-6

Strauss, P., Cook, A., Watson, V., Winter, S., Whitehouse, A., Albrecht, N., ... & Lin, A. (2021). Mental health difficulties among trans and gender diverse young people with an autism spectrum disorder (ASD): Findings from trans pathways. *Journal of Psychiatric Research*, *137*, 360-367. https://doi.org/10.1016/j.jpsychires.2021.03.005

Taimre, L., Robinson, J., Phillips, L., Bailey, E., & Nguyn, B. (2021, December 9). *Exploring the perspectives of young autistic people with lived experience of suicidal ideation/behaviour and self-harm* [Conference presentation]. Australasian Society for Autism Research, Melbourne, VIC, Australia.

Tervalon, M. & Murray-Garcia, J. (1998). Cultural humility versus cultural competence: A critical distinction in defining physician training outcomes in multicultural education. *Journal of Healthcare for the Poor & Underserved*, *9*(2), 117-125. https://doi.org/10.1353/hpu.2010.0233

Thomas, S., Hovinga, M. E., Rai, D., & Lee, B. K. (2017). Brief report: Prevalence of co-occurring epilepsy and autism spectrum disorder: The US National Survey of Children's Health 2011–2012. *Journal of Autism & Developmental Disorders, 47*, 224-229. https://doi.org/10.1007/s10803-016-2938-7

Uljarević, M., Hedley, D., Cai, R-Y., Hardan, A. Y., & South, M. (2020). *Anxiety and depression from adolescence to old age in autism spectrum disorder.* In F. R. Volkmar (Eds.), *Encyclopedia of Autism Spectrum Disorders.* Springer.

Van Orden, K. A., Witte, T. K., Cukrowicz, K. C., Braithwaite, S. R., Selby, E. A., & Joiner Jr, T. E. (2010). The interpersonal theory of suicide. *Psychological Review*, *117*(2), 575- 600. https://doi.org/10.1037/a0018697

Victorian Government. (2021). *Understanding intersectionality: Definition of intersectionality and how it can lead to overlapping of discrimination and marginalisation.* https://www.vic.gov.au/understanding-intersectionality

World Health Organisation. (2008). *Preventing suicide: A resource for media professionals*. https://www.who.int/mental_health/prevention/suicide/resource_media.pdf

World Health Organisation. (2021). *Suicide* [Newsroom fact sheet]. https://www.who.int/news-room/fact-sheets/detail/suicide

World Health Organisation. (n.d.). *Suicide Prevention.* https://www.who.int/health-topics/suicide#tab=tab_1

Zero Suicide International. (n.d.). *Zero suicide: Healthcare that believes no one should die alone and in despair*. https://zerosuicide.org/

Zero Suicide International of Australasia. (n.d.). *Zero suicide healthcare.* https://www.zerosuicide.com.au/

Appendix A – ASfAR Conference Schedule (Dec 9, 2021)

CONFERENCE SCHEDULE

8.30 – 9.00am: Check in

9:00 – 9.05am: Intro and housekeeping by MC Dr Karien Hill

9.05 – 9.10am: Welcome to country; ASfAR President, Professor Andrew Whitehouse; OTARC Director, Professor Cheryl Dissanayake

9.10 – 9.20am: Opening address: Parliamentary Secretary for Mental Health, Parliamentary Secretary to the Premier, Victoria, Mr Steve Dimopoulos MP

9.20 – 9.25am: Suicide Response Project launch: Professor Cheryl Dissanayake

BREAK – 10 min

9.35 – 10.25am: Keynote Speech 1: Dr Brenna Maddox (USA)
Deputy editor for the journal Autism in Adulthood.
"Recognizing and reducing suicide risk in autistic people." (30 min + 20 min for Q&A)

BREAK – 5 min

10:30 – 11.20am: Special Guest Speaker: Lisa Morgan (USA)
Certified autism specialist and autistic author of "Living Through Suicide Loss with an Autistic Spectrum Disorder." (30 min + 20 min for Q&A)

BREAK – 10 min

11.30 – 12.30pm: Discussion Panel 1: Lived Experience Panel, facilitated by Dr Jac den Houting, Macquarie University. (40 min + 20 min Q&A)

12.30 – 1.30pm: LUNCH BREAK:
Poster presentations/Sponsor booths/Entertainment/Video chats (60 min)

1.30 – 2.20pm: Keynote Speech 2: Associate Professor Jo Robinson, University of Melbourne, Head of Suicide Prevention Research at youth mental health service Orygen. (30 min + 20 min for Q&A)

BREAK – 10 min

2.30 – 3.30pm: Discussion Panel 2: Policy, Clinical practice and Service Provision Panel, facilitated by Chris Templin of advocacy and support organisation AMAZE (40 min + 20 min Q&A)

BREAK – 30 min

4.00 – 4.50pm: Keynote Speech 3: Professor Phil Batterham (ANU, Canberra); Centre for Mental Health Research. "Understanding and preventing suicidal behaviour in the general population." (30 min + 20 min for Q&A)

4.50 – 5.00pm: Closing Remarks & ECR Award Presentations: Dr Darren Hedley, La Trobe University

68

Appendix B – Roundtable Agenda (Dec 10, 2021)

Welcome		
8:00 am to 8:20 am	Acknowledgement of country (Darren) Welcome to the Roundtable (Darren) Brief introductions (Darren) Goals & overview of the Forum (Darren)	Chairs: Dr Darren Hedley Dr Sarah Cassidy Chris Templin Dr Susan Hayward
Breakout Room 1 Discussion		
8:20am to9:00am	Dr Rachel Moseley Dr Erin Bulluss Dr Jac Den Houting Axel-Nathaniel Rose Lisa Morgan Dr Sarah Cassidy Alex Haschek	Moderator: Dr Susan Hayward
Breakout Room 2 Discussion		
8:20am to9:00am	Dr Brenna Maddox Dr Aspasia Stacey Rabba Prof Robyn Young Professor Kairi Kõlves Dr Darren Hedley A/Prof Mark Stokes	Moderator: Chris Templin
Group Discussion		
9:00 to 9:10am	10 min Break	
9:10 am to 9:55 am	A sharing of summaries from thebreakout room discussions Discussion on differences encountered Future directions	Moderator: Dr Sarah Cassidy

Purpose and Intent of the Roundtable

This Roundtable has been convened to allow speakers and participants at the ASfAR conference to:

1. synthesise and summarise key themes and priorities from the conference,
2. find out what we don't know yet, and to
3. translate research and lived experience expertise into practical measures and policy recommendations to improve the lives of autistic people.

Along with a conference wide feedback survey (delivered to all attendees on Monday the 13th of Dec), the discussions from this Roundtable will be used to develop a suite of reform priorities that can be used in public advocacy activities and direct future research. The Roundtable will allow participants to highlight the opportunities for practical reform to be shared with political parties, with the aim of driving systemic change to the benefit of autistic people globally.

Breakout Room Discussion Questions

1. What do you think were some of the most important themes/issues (2) raised at the conference? (40 min) It may help to think of themes that are relevant to one or more of the following:
   (i) Autistic people
   (ii) Policy makers
   (iii) The mental health sector
   (iv) Researchers
2. What practical changes would improve the lives of autistic people around these themes?

Whole Group Discussion Questions

1. Breakout Room 1 feedback of theme/s (5 min)
2. Breakout Room 2 feedback of theme/s (5 min)
3. Discussion and suggestions from the breakout room themes (35 min)
   (i) Identify any missing themes/issues
   (ii) How can we make these themes/issues visible and important to researchers, professionals, and policy makers?

Authors - Roundtable Participants

Dr Darren Hedley
(Co-chair, Senior Research Fellow, OTARC, La Trobe University, AU)

Dr Susan Hayward
(Co-chair, University of Melbourne, AU)

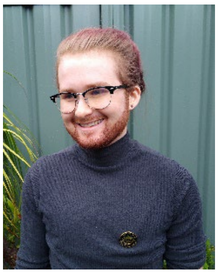
Chris Templin
(Co-chair, Amaze Senior Policy Analyst

Dr Sarah Cassidy
(Co-chair, University of Nottingham, UK)

Dr Rachel Moseley
(Bournemouth University, UK)

Dr Erin Bulluss
(Private practice/Reframing Autism, AU)

Dr Jac Den Houting
(Macquarie University, AU)



Axel-Nathaniel Rose
(Lived Experience, Expert AU)

Lisa Morgan
(Consultant, USA)

Dr Brenna Maddox
(University of North Carolina-Chapel Hill, USA)

Dr Aspasia Stacey Rabba
(Monash Health, AU)

Prof Robyn Young
(Flinders University/Private Practice, AU)

Prof Kairi Kõlves
(Griffith University, AU)

A/Prof Mark Stokes
(Deakin University, AU)

Alexandra Haschek
(OTARC Research Officer, La Trobe University AU)