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December 9, 2021 Melbourne, Australia

# Mental Wellbeing & Suicide Prevention in Autism: Bringing Autistic People, Researchers and Health Professionals Together

Abstracts and Transcripts

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# The organising committee members:

Perrin Date Melinda Denham Dr Melissa Gilbert Dr Elfriede Ihsen Alex Haschek Dr Darren Hedley

Margaret Laughton Professor Alison Lane Michael Leahy Radhika Nair **David Murphy** (www.murphythejournalist.com)

# **Acknowledgements**

In the spirit of reconciliation, the ASfAR Mental Wellbeing and Suicide Prevention in Autism 2021 organising committee acknowledges the Traditional Custodians of Country throughout Australia and their connections to land, sea and community. We pay our respect to their elders past and present and extend that respect to all Aboriginal and Torres Strait Islander peoples today. The Olga Tennison Autism Research Centre is located on Wurundjeri land of the Kulin Nation.

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.



Transcript Special Guest Speaker: Lisa Morgan (USA), certified autism specialist and autistic author of "Living Through Suicide Loss with an Autistic Spectrum Disorder."

Hello. Thank you for inviting me to speak today. I appreciate the opportunity to be here and share my story. So, today I'm going to talk about autism and suicide through the lens of autism and lived experience. Suicide has made a significant impact on my life. I attempted to end my life. My husband of 29 years, self-diagnosed as autistic, died by suicide. My nephew died by suicide. A young 24-year-old autistic man who I had known since he was two years old died by suicide. Suicide has also changed the trajectory of my career and started me on a journey of advocating for crisis supports and suicide prevention resources for autistic people.

So, first, with autism, being an inherent difference in brain structure, we autistic people experience the world differently. We communicate differently, which, I suppose, can be strange to non-autistic people. I've learned throughout my life that the majority of people are not comfortable with strange, weird or inherently different people. So much so that autistic people are continually feeling pressured to fit into a society that makes little sense to us most of the time. We live in an environment that can be too loud, exceptionally bright, with overbearing smells and disagreeable colours.

We are misunderstood, alienated, fired, not hired, rejected, and know that we must mask who we are to be accepted. Autism is a different way of being with its own strengths, challenges, and way of communicating, but, because we are different and can't conform to mainstream's social expectations, many autistic people come to think of themselves as less than, or not good enough, or even failures.

We eventually accept what society continues to think about us, until we live with internalised ableism and just torture ourselves into perfectionism, trying to do everything right. We become more than overwhelmed. We have unmet needs, experience thwarted longing, mask our true selves. Many of us succumb to autism burnout. So, there are a lot of autistic people who can think of no other way to just make it stop than to escape through death.

Suicidality is a crisis in the autism community. It's the leading cause of death for us. The leading cause of premature death for us. Autism-specific suicide prevention resources can help professionals to better support autistic people in crisis. Resources can help professionals to know how to communicate with autistic people, to be more culturally competent and understand the unique risk factors and warning signs in autistic people.

Resources could also prevent unintentional harm through either mistakenly believing and autistic person is suicidal and then acting upon that belief and further traumatising them in an effort to help, or not understanding that an autistic person is suicidal and dismissing the warning signs, because they are different than what most other suicidal people exhibit.

Very often we reach out for support, we don't get our needs met. Not because people don't care, but because they likely can't see the autistic person in front of them, or they do not understand the unique ways that autistic people communicate and experience the world. Or, when we reach out for support, we are unintentionally harmed by well-meaning professionals who believe they are helping but are not, which is why they must let us help them help us. tw

Autistic people must be part of the solution. So, let me tell you some of my personal experiences to help you see what I mean. For me, my lived experience with suicidal ideation started when I was in my teens. To my teenage brain, suicidal ideation brought a sense of

relief. Knowing, if the emotional pain and overwhelm got too bad, I had a way to stop it.

That relief, in some way, helped me to keep trying, to keep going, to not get to that point of no return. I honestly do not know exactly when it started. For me, suicidal ideation was a gradual big idea that solidified into a thought over time. Again, it was a comfort to know I could stop the emotional pain I lived with, if it got too bad. Looking back, the best year of my life was kindergarten.

I can remember just being a kid in [Mrs Rose's] kindergarten like every other kid. I was accepted, I didn't feel different. My memories are playing and learning and having fun. My class got to go on a local television show where I was one of the kids chosen from the audience to play a game. At the end of the year, we sat for silhouettes of our profiles by casting our shadows onto white paper that our teachers traced with pencil and then transferred to black paper.

I was excited and fascinated by that whole process. The bullying, rejection and socially traumatic realisation that I was somehow inherently, intrinsically different from my peers started the very next year in first grade and has continued throughout my life, even up to now. My lived experience with suicide started in 2014. I was in a really rough place and had been for several years.

I had been experiencing abuse due to a mental illness my husband suffered from, which caused him to rapidly deteriorate into a stranger. I was raising my two youngest children basically alone, although completely alone would have been easier. I was working outside of the home, and I was just very much alone. I did not know how to reach out to other people for help.

Past experiences had taught me to struggle through difficult circumstances alone. [I did not know] how to ask for help, and I did not know who to ask for help, but I did get to the point of trying. I was continually reminded that I don't see things like most other people. First, I tried telling our primary care physician, who my husband and I both saw, and with whom I had permission to share my husband's medical information, that I was concerned my husband was suffering and possibly suicidal.

I thought I was clear in reporting his symptoms. But, after talking to my husband, our physician came back and told me my husband was fine and I just needed to be a better wife. As I'd often heard in my life, the problem was me. During the same time period, I also found an organisation called the Hope Centre that helped women in situations like mine. I made an appointment to talk to someone there.

But, haunted by past experiences of being misunderstood, bullied, and rejected for me being me, I stood outside that building on the day of my appointment, very unnerved, afraid, and just willing myself to go inside. I eventually did, and soon found myself sitting in front of a lady, telling her of my situation. It felt completely uncomfortable and extremely risky. I felt confused afraid, embarrassed, and vulnerable.

It was really the first time I went that far into detail. I will never forget what happened when I was done reporting my situation. She laughed. She laughed, and she started asking me more questions, not to understand or help me though. It seems like her questions were to catch me in a lie. She didn't believe me. She kept saying she'd never heard of a situation like mine before. I left before she or anyone else could see me start to cry. I was completely alone.

Then, in October of 2014, I moved out of my marital home with my two young boys for safety purposes. The only place I could find by myself was horrid. It was infested with fleas, there were cockroaches, it smelled sour, was in a bad part of a city, and came with its very own rat. It was not a place of peace and safety. Although I eventually fixed all of those problems, I still felt like my whole life was a failure, and, in my effort to keep my boys safe, I brought them to a

place none of us felt okay living in.

It seemed the more I tried the harder things got, the worse my situation became, and night after night after night I was consumed by emotional pain, guilt, and confusion. I could not sleep until one night in December, convinced my kids would be better off without me, I could only think about how to make all of the pain, all of the confusion, all of the struggling to just stop. I survived, but things only got even more difficult, again, as I reached out for help.

I was judged harshly by the professionals in the hospital the day after my attempt. I was asked questions like, why did I ever have children, why did I stay with my husband for so long? Instead of them trying to figure out why I wanted to leave this world and then help me to stay, I was misunderstood, accused, ignored, patronised by the professionals to whom I reached out for help.

After being there for five days, somebody came up to me and said, oh, is this your first day? I felt invisible. No one could see me, no one could help me. I could not get anyone to listen to me. I couldn't find the right words to say. People were asking me why I had reached out for help or told anyone. I thought I finally was reaching out for help and telling people. But remember, a big part of autism is difficulty in the area of social communication.

So - both externally and internally. So, I couldn't externally communicate what I couldn't internally understand. I was in mental anguish and confused, scared - couldn't sort out my intense emotions, completely worried about my boys, and then the help I was getting only exacerbated it all. What I felt at the time, that no one cared, was more likely about no one being able to understand me.

Then, when my husband died by suicide in 2015, just about six months after that, my life got exponentially more difficult than I could have ever imagined, and I was thrust into a world of social communication challenges in the aftermath of my husband's suicide. I had confusing conversations and was misunderstood by so many different people in the settling of his estate.

Like insurance people, the human resources department at his place of employment, lawyers, the mortgage company, the coroner, the police, the people repairing my marital home, the realtor, my boss, bankers, creditors, neighbours, and even family who were still in deep grief from my nephew's suicide. I had no support. People I did know before my husband died had stepped out of my life.

They just did not know what to say or what to do. I knew things had to change for the better. I didn't want other autistic people to have the same experience as I did. So, I wrote my first book in 2016 about living through suicide loss as an autistic person. Then, out of the continuing necessity of supporting myself and wanting to support other autistic people, I started a conversation with a suicide prevention organisation called the American Association of Suicidology, AAS, about autism and suicide.

I eventually led the development of autism-specific resources written directly from research findings in collaboration with the autism and suicide committee I founded in 2018 at AAS. The crisis supports for the autism community toolkit was originally written to help crisis centre workers identify and communicate with autistic people who call or text for help.

I had texted a crisis centre one night, feeling very, very alone in the world. Only after a brief conversation, to be put on hold and then have the person end the call. I felt more alone after the call ended than I did before. I knew the person I had communicated with did not understand me. That in itself conjures up a deep sense of loneliness. It was after that call that I made the decision to write the crisis tool kit.

Being diagnosed later in life, at the age of 47, was a factor in my not having the social skills

needed to reach out for help. But still, if the professionals I interacted with knew more about autism through autism-specific resources written in collaboration with autistic adults, perhaps I could have had a better change of receiving the help I needed.

Maybe my primary care physician would have listened and understood more when I confided in him about my fear that my husband was suicidal, instead of telling me I just needed to be a better wife. Maybe my nephew or my young autistic friend could have also been heard as they struggled. Looking back, I think my calm demeanour, or masking, my literal way of communicating and not using any excess words to elaborate did not convey the urgency of our situation to our primary care physician.

Also, although I had been diagnosed as autistic at the time, I still didn't know enough about autism to self-advocate. Perhaps the lady at the Hope Centre would have reacted differently than with laughter, if she knew more about how to communicate with autistic people and more about autistic people in general. Maybe my experience at the hospital I ended up in after my attempt could have been supportive and helpful instead of traumatising, alienating and confusing.

I don't know. What I do know is autistic people are in need of being understood for who they are as well as how they communicate and experience the world. The autism community needs people who are open to learning new ways to communicate and who are capable of changing things up in order to help us, not in the typical way, but in the way we need to be helped, as autistic people.

For example, we need professionals to slow down and let us process situations, words, directions, and whatever environment we're in, when we're receiving help, and figurative language is confusing, so use literal speech. Social nuances are difficult, so communicate in a straightforward way, using as few words as possible. The more honest you can get, the better it is for us.

Understanding that masking may cause us to look calm, even while in a crisis is imperative. If we say we are emotionally distraught with a straight face, no tears, no apparent anxiety, and with a calm demeanour, listen to our words, knowing that we may be making or shutting down or completely overwhelmed. Learn about ableism. Just try to remember who you are helping, when you're working with autistic people.

I know it's possible to do that, because I have lived experience around the fact that it can work. It takes a humble soul, a heart for helping people, and a mind that's open to new ideas. Someone who can see beyond themselves and know the differences of people from minority groups are just as valid, important, and worth understanding as the sameness of the people from mainstream society.

Someone who understands a person's worth and potential are not depended on how well they conform or fit in with the majority of society. I was fortunate to have met that someone in real life a little over three years ago. Someone who is helping me change my story from striving to thriving. I've slowly been meeting more supportive understanding people like her through my advocacy work.

Still, in the thousands of people I have met in my lifetime, I can name only a few who get it. As an aside, keep in mind that I also know people who work or volunteer in associations specifically mean to help autistic people and still only a few people I know have taken the time to truly understand me and other autistic people. I have a few people in my life that support me and I trust.

As many as I can count one hand. I'm one of the lucky ones, to have that many. But know this. Learning to help autistic people is not difficult. Although I'm sure it takes effort. It's about being not only culturally aware, but culturally humble. It's about accepting people for who

they are, not who is most convenient for them to be, and about seeing the potential and the value and the strength in the differences.

Finally, again, let us help you help us. We know autism. We are autistic. We know more about the reality of living with autism in today's society that 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.

Again, let us help you help us. Thank you for being here today. I hope your interest in this subject will continue and contribute to some really helpful changes for autistic people in need.

# **KEYNOTE SPEECHES**



Transcript Keynote Speech: Dr Brenna Maddox (USA), PhD, Deputy Editor for the journal Autism in Adulthood.

"Recognizing and reducing suicide risk in autistic people."

Hello, I'm so honoured to be here today with you all, virtually, and I want to thank the conference organisers for putting together this incredibly important and timely event. Thank you for inviting me to be part of it. Wish that I were there with you all inperson, but we will make the most out of this virtual experience and I'm excited to answer your questions live during the Q&A period.

First, a quick note about the language that I will be using in this presentation today. Personally I was trained in graduate school to use person-first language, or person-with-autism, as the most respectful and preferred way to refer to individuals on the spectrum. So I used person-first language for many years. Then more recently, my close autistic collaborators, and the people that I work with on several projects, some of which you'll hear about today, express their preference for identity-first language, or autistic person. There have been several articles published in the last few years that highlight the preference for many people on the spectrum of identity-first language.

So I just want to note before I jump into all my slides today, that I will be using identity-first language to respect that preference. For anyone who's interested in reading more about this use of language and how to avoid ableist language, I would highly recommend checking out this article published in Autism in Adulthood last year.

So why are we all here today at a conference focused on suicide prevention for autistic people? As you all know, we're focused on this topic because there is a growing awareness that suicide is a leading cause of early death in the autistic community. The prevalence of suicidal thoughts and behaviours are significantly elevated in autistic children, adolescents, and adults, compared to the general population.

This new article just came out a couple of months ago, by the time of this conference; it's already getting a lot of press, which I think is good again to increase that awareness. This paper is a systematic review in meta-analysis of 31 studies, and it finds that the odds of self-harm in people on the spectrum is more than three times the odds in people not on the spectrum. This article is really, as I mentioned, raising awareness, again that both children and adults on the spectrum are at this increased risk for self-harm and suicidality.

So knowing the elevated prevalence [estimates], I think a natural next question is why? Right? What makes autistic individuals more likely to think about, attempt or die by suicide? We know that factors known to increase the risk of suicide in the general population are more common in autistic individuals, and I've listed just a few examples up here on the slide.

However, in studies that have had comparable rates of some of these factors in the two groups – on an autistic group and a non-autistic group, even when these factors are similar across the two groups, the autistic individuals still show an increased risk of suicidal thoughts and behaviours. Of course this suggests that we need to consider additional factors, and some may be more specific to autistic individuals.

So this list of risk factors of suicidality is in no way an exhaustive list, but some of these risk factors are the most studied, and the most afforded as risk factors, and also some that may be specific to autism. This first one, I'm sure is not a surprise to anyone listening, co-occurring psychiatric conditions in autistic individuals is a significant risk factor for suicidal thoughts and behaviours. There was a large national study out of Denmark earlier this year, and the research team found that of that group of autistic adults, either attempted or died by suicidal, more than 90 per cent of them had a co-occurring psychiatric condition.

We also know that a lack of social support and similarly, or more generally, unmet support needs, can be a risk factor for suicidality in autistic people. Dr Hedley and Dr Cassidy and their teams have done some really wonderful work to show, and to highlight how these risk factors need to be better understood. Camouflaging or masking is somewhat newer in the literature in getting attention as a potential risk factor for suicidality.

The next one up here is a late diagnosis. So we know that individuals who receive their first-time autism diagnosis in adulthood are at an increased risk of suicidality. Several studies suggest that autistic females are at a particularly increased risk for suicidal thoughts and behaviours. Then this last one, autistic burnout – again this is a somewhat newer term in the field and it's defined as a syndrome conceptualised as resulting from chronic life stress and a mismatch of expectations and abilities without adequate supports.

If you're interested in learning more about autistic burnout, Dr Raymaker and colleagues published this excellent article in the Journal Autism in Adulthood last year and they really describe, define and summarise the potential negative consequences of autistic burnout, including suicidality.

So we were just talking about risk factors which are characteristics or conditions that make it more likely that individuals will think about, attempt, or die by suicide. Warning signs, on the other hand, indicate a more immediate risk of suicide, and unfortunately there is much less research in the autism field right now on suicide warning signs compared to risk factors.

To hopefully start to close this gap in the research, and particularly in terms of practical guides, Lisa Morgan, whom you're about to hear from in this conference, had a brilliant idea to develop a proposed set of warning signs for autistic people. As I'll show on the next slide, she invited a small group of us to work on this guide. This was just recently published – I have the link there on the slide. That is Lisa's website, and this new Warning Signs of Suicide in Autistic People resource is featured on the main page of the website.

As you can see here, this is a resource that's based on research findings and expert consensus. Our motivation to develop this resources was that warning signs of imminent suicidal behaviour in the general public do not always represent unique needs of the autism community. So as I mentioned, Lisa had this wonderful idea to pull together an international group, and brought us together to work on this resource, the development of this resource, from July 2020 all the way until August 2021.

So you can see the co-authors are pictured up here, Dr Teal Benevides, Dr Mary Donahue, Dr Sarah Cassidy, Mirabel Pelton, and myself — all worked closely with Lisa Morgan to develop this resource. One thing I really admire about this team is that we cover a wide range of experiences. Many of us have multiple experiences and roles, including autistic people, researchers, practitioners, and those with lived experience of suicide loss and suicidality.

This guide is designed to enhance discussions about suicide risk with autistic people; we want to make clear that it's not a substitute for professional support or professional risk assessment. The goal is to improve individual's understanding. So this could be mental health professionals, or physicians, it could be family members and friends – improving their understanding about these potentially unique warning signs of suicidal behaviour in autistic people.

I think Lisa will touch on this more in her presentation, but we really went into this work together, wanting to prevent both kind of sides of these devastating consequences that can occur when someone does not understand warning signs of suicide in autistic people. So misunderstanding a suicide, a warning sign, in an autistic individual who lead to someone reacting and intervening without really understanding that what the autistic person is experiencing can be traumatic and can lead to unintentional harm.

Then, on the other side of things, if we don't recognise something as a warning sign, and we don't act or we don't intervene, that can of course have devastating consequences as well. So our hope is that this resource will get into the hands of more people and help the improve that understanding.

A little bit of information about the structure of the resource. We proposed, again based on research and expert consensus, a set of 10 warning signs — so those are listed, followed by brief scenarios or case examples explaining them. Emerging research findings, where available, because like I mentioned there is not as much research in this area, unfortunately. We also have a few pages of additional resources about autism and suicide prevention. Then a one-page summary to use in real time.

So you may be wondering, what are these warning signs? I do not have enough time today to go through all of these in-dept, but I will list the 10 warning signs here on the slide. I do want to note that the warning signs are contingent upon a marked increase, or a change of specific experiences or behaviours that are different than usual for the individual. So this really highlights how important it is to get a good understanding of the individual's baseline. I also want to note that, for many autistic individuals at imminent risk of suicide, more than one of these warning signs would be present.

The first is sudden or increased withdrawal from typical activities, or from social interactions. No words to communicate acute distress. So we're hearing this from more and more autistic individuals as an experience that they've encountered. They want to communicate that they need help but they are at a loss of words to do so. A current traumatic event. A marked increase in the rate and/or the severity of self-harm. A worsening of anxiety and/or depression.

A new focus on death-related topics that are not an intense interest for an individual. So we recognise that, for some individuals on the spectrum, one of their intense interests may be related to death. I remember working with an individual who was really interested in researching the cause of death of celebrities and that was something that we would talk about in most of our sessions together. It was not a new focus, and it was an intense interest. So we're trying to distinguish in this resource that you need to be looking for that new focus on death-related topics that are not an intense interest.

We know that suicidal thoughts and ruminations can take a perseverative quality in individuals on the spectrum, and this is definitely something to look out for. Seeking means

or making plans for suicide, or suicide rehearsal. Statements about no reason for living or no sense of purpose in life. Then finally, hopelessness.

So I encourage you all to read more about these warning signs from the free publicly available resource, and I want to thank the co-authors again for making this resource available. It was really, really inspiring to get to work with this group, and we're all excited to disseminate this resource more, so thank you for the opportunity to talk about it today on behalf of this wonderful team.

Before moving on, I do want to provide one example of a case scenario from this resource. So this is the case scenario from sudden or increased withdrawal, and I'll read this to you now. Lucia routinely withdraws for self-care. Her family and friends understand the need she has for alone time. They know Lucia will be spending time in her room for a while after school, work, and social events, and then will immerse herself in making clay animals.

Suddenly, Lucia's family and friends noticed she was spending more and more time in her room. Lucia goes straight to her room when she gets home, only coming out for meals. She continues to participate in her usual activities, although she doesn't want to, and takes longer to regulate afterwards. Lucia is no longer interested in making her clay animals, and she has not replaced that passion with another.

So a few things to note about this scenario. Lucia, like many autistic people, values alone time to recover after intense social events. However, sudden or increased social withdrawal, which is unusual for Lucia, could indicate a mental health problem such as depression. It is particularly concerning here that Lucia's increased social withdrawal is coupled with her reduced interest and pleasure in a previously intense interest, making her clay animals.

Dr Cassidy and colleagues have recently published some research that suggest that, together, these are unique warning signs for depression in autistic people. We know that depression can come with suicidal thoughts.

Before wrapping up, I do want to highlight a few crisis supports and resources, while we're talking about this topic of suicide prevention. Lisa Morgan, in collaboration with the American Association of Suicidology, or AAS, the Autism in Suicide Committee, published this Crisis Supports for the Autism Community, which is another free publicly available resource. The link is up here on the AAS website, and the purpose of this toolkit is to help crisis centre workers, and other professionals, in identifying and supporting autistic callers or texters who are in crisis.

Autistica also recently collaborated with researchers, clinicians and community members to create a new mental health resource for professionals supporting autistic children and young adults at risk for suicide.

Another resource, or intervention, that I want to note here is the Safety Planning Intervention. Dr Shari Jager-Hyman from the University of Pennsylvania and I received some funding from the FAR fund a few years back to adapt the Safety Planning Intervention for Autistic Adolescents and Adults, based on stakeholder feedback and based on the established modifications to cognitive behavioural therapy for individuals on the spectrum. Because the Safety Planning Intervention is a cognitive behavioural intervention.

For anyone not as familiar with the Safety Planning Intervention, or SPI, it's an evidence-based suicide prevention intervention in the general population, so it has not been rigorously tested for autistic individuals in the past. It's a brief individually tailored intervention, and that individually tailored piece is a nice strength when working with autistic individuals. We can really tailor it to match that individual's interest and strengths and needs. The version of the safety plan that Shari and I modified is the Stanley and Brown version.

So as we were wrapping up our Farfund study, PCORI, or the Patient-Centred Outcomes Research Institute, released a funding announcement focused on brief interventions for suicide prevention in youth, and they were specifically interested in tailored versions, or culturally-adapted versions for at-risk sub-groups. Shari and I were delighted to see that PCORI recognised that individuals with developmental disabilities are an at-risk group for suicide.

So with a truly amazing team, that I will highlight here in a moment, we proposed a large-scare comparative effectiveness study, and we are very excited that we will be launching this study next month with the support of PCORI. So I want to end by sharing a little bit of information about that study, and I'm happy to answer any questions during our Q&A time.

So this is a five-year study, and we are very fortunate to have the opportunity to partner with four different health systems here in the United States – University of North Carolina at Chapel Hill, where I work, Kennedy Krieger Institute, the Children's Hospital Philadelphia, and Nationwide Children's Hospital. The main focus of this study is to compare the effectiveness of that tailored safety planning intervention, with and without a structured follow-up component. The interventions will be delivered as standard care.

So what's exciting is that these heath systems have agreed to adopt a tailored safety planning intervention as part of routine clinical practice and will be embedding the research activities into their routine clinical practice.

The thing I'm perhaps most excited about is this community-based participatory research design. One of the biggest honours of my career was when the co-lead of the Autistic Adults and Other Stakeholders Engage Together, or AASET group, reached out to see if I would be interested in partnering with AASET on this PCORI proposal. Of course, I said yes – this is an amazing group. I'm co-led by Dr Stephen Shore, pictured here, and Dr Teal Benevides, pictured here. Lisa Morgan is also part of AASET, along with many other autistic adults and other stakeholders.

AASET was created through a PCORI stakeholder engagement award back in 2017, and they had funding for two years to work on this goal. To meaningfully include and engage autistic stakeholders in identifying priorities and methods to support patient-centred outcomes research, in true collaboration with autistic people. So we talk a lot about authentic autistic alliance and meaningful involvement.

During that time they established a Community Council, and what I think is so impressive is, even after the PCORI engagement award funding ended, this group has continued to work together, to publish, to present together, and to drive this mission forward. So it's again such an honour to be able to partner with them on this PCORI study.

So this is my last slide – there's a lot going on on this slide [laughs] – it's a little visually overwhelming, so I apologise. I'm not going to go through all of it, but I just want to highlight what a big strong team we have for this PCORI study on Suicide Prevention in Autistic Individuals. As you will note here, we have a strong stakeholder engagement core that really is at the core of our team, co-led by Drs Shore and Benevides, and the AASET Community Council is a big part of that as well as a multi-stakeholder advisory board.

We also are excited and really fortunate to have autistic adults be part of our clinician training team and our implementation outcome evaluation team. You may notice or recognise Lisa's name here; Lisa will be co-leading the clinician training team with us. So getting into those health systems, we're going to be able to train a large number of clinicians on how to best screen for, assess and manage suicidality in autistic individuals.

So we are really looking forward to getting started, and hopefully at some point soon we can come back and share some of those results with you all. So thank you so much for

your attention today. I want to acknowledge the wonderful community partners, as well as academic collaborators who make this work possible and from whom I continue to learn so much every day.

Of course, thanking the research participants who agree to participate in these studies, and the funding sources. Also, again, thank you to everyone in this audience for your attention, and I'm looking forward to answering your questions and hearing your thoughts during the discussion period.

Take care.



Transcript Keynote Speech: Associate Professor Jo Robinson, University of Melbourne, Head of Suicide Prevention Research at Youth Mental Health Service Orygen.

Hi everybody, and thanks so much for having me here today. I'm Jo Robinson and I lead the Youth Suicide Prevention Research Group at Orygen, which is part of the University of Melbourne.

Before I get going, I would like to acknowledge the traditional owners of the lands that I'm joining you from here today, the lands of the Yalukit-Willam people of the Boonwurrung,

and pay my respects to Elders past, present and emerging. I'd like to extend that acknowledgement and respect to the traditional elders of the lands that others are joining us from today, and to any Aboriginal or Torres Strait Islander people in our audience. So thank you and welcome.

So today I'm going to be talking a little bit about some of the work we're doing in my team in youth suicide prevention. This is what we'll try and get through and we'll see how I go for time. But I'll give you a little bit of an overview around what's happening in terms of the epidemiology of suicide and self-harm in young Australians, and some of the risk factors that we're seeing. Then what I'll do is give a bit of a snapshot of some of the work we're doing around youth suicide prevention in different settings, and I'll talk a bit about online settings, school settings, and then in the clinic.

I'd like to finish, if time permitting, with just a couple of words really about youth participation in suicide prevention, and specifically actually suicide prevention research. Okay, so let's get into it.

So in terms of background, unfortunately suicide is the leading cause of death amongst young people here in Australia. What you can see from the graph here is that suicide rates have been steadily increasing in young people over the last 10-year period. So yeah, as you can see – so this graph here, this line here is for young males aged 20 to 24, steady increase. Same for young males aged 15 to 19. We're also seeing lower numbers and lower rates, but also a similar trend in young females, in particular females between the aged of 15 and 19. In fact we're also starting to see increases in suicides in females even younger.

That means that suicide is the leading cause of death here in Australia, and as I said, rates have been rising over time. If you look at the rates here, what you can see is, overall, in 2020 there was just over 3000 deaths, suicide deaths across Australia, across the age range. Three hundred and eighty-one of those were by young people. So what we see is a rate of 12 – just over 12 per 100,000 population across the age range. But when you look at young people, and

in particular young males, what you see is a rate of nearly 25 per 100,000, so significantly higher rates in that younger cohort, particularly young males.

Rates are higher generally in regional areas compared to the capital cities, with the exception of South Australia I think. Tragically, twice as many First Nation Australians die by suicide, compared to their non-Indigenous counterparts. So we definitely need to be doing a better job of looking after our Aboriginal and Torres Strait Islander young people. We also see high rates in young people who identify as LGBTQIA+, although I have to say that the quality of data collected around mortality in this population is pretty limited. Again, we could do with doing a bit of a better job of recording what's happening across different sectors of the population.

Just finally on this, I'd just like to note that youth suicides are over twice as likely to occur as part of a suicide cluster than adult suicide. So that's from some work that we did here in Australia, [the MAP] suicide clusters across Australia a few years ago, and youth suicides accounted for over five per cent of suicide deaths, compared to 2.5 per cent in adult suicides.

So here we're looking at self-harm. We know self-harm is one of the biggest risk factors for future suicide, and young people do have the highest rates of hospitalisation for self-harm across the population. So here what we start to see are these really – these higher rates amongst young females. So as I was saying before, rates of suicide tend to be highest in young males, although rates in females are increasing. What we're seeing here is sort of the reverse of that where we see higher rates of self-harm in young females, but actually increasing rates of self-harm in young males, and I'll show you a couple of graphs in a second that show what's been happening over time.

But as you can see here, around a quarter of young women report self-harming at some point in their lifetime, and this is young women up to the age of 24. In males, lifetime rates are around 18 per cent in the 20 to 24 year old age bracket, and 11.6 per cent in the slightly younger age bracket. We do see particularly high rates of self-harm in our clinical samples, and self-harm typically onsets around that period of early adolescence, so around the time associated with puberty.

Although for many people it does remit with age, it is distressing, in its own right, and associated with a whole range of other negative outcomes, including subsequent self-harm, but also subsequent death by suicide. So it is a behaviour or a problem that we need to be taking seriously when it does occur.

We've also heard reports, and I'm sure many of you will have heard these too, certainly across the media, significant rise in rates of young people presenting to the emergency department with self-harm during the course of the pandemic. Also some evidence to indicate increased use of mental health services, increased psychological distress, and to a certain extent, particularly in these younger populations in young males, increased rates of youth suicide as well.

So this gives a little bit of a snapshot of what's been happening over time. So these are ambulance attendances, from the period of 2018 up to 2021, so it's just this last couple of years across the age range, and again you can see here, this is young males, steady increases. But quite striking increases in young females. So these are ambulance attendances for self-harm; we've got similar data that's also for suicidal ideation and suicide attempt, and the same pattern is seen. So these really striking increases in young females under the age of 24.

This next chart here talks about hospitalisations for self-harm. So again this is the graph for young males, or for males across the age range actually. This is the graph for females, and again quite striking that the highest proportion of hospitalisations for self-harm are occurring in young females. This is the age group [under] 15 to 19, so particularly high. This is the group for the 20 to 24 year olds.

So what you can see here, we've got this problem basically with increasing rates of distress, increasing rates of self-harm, high rates of presentation to hospital and hospitalisation for self-harm, and high rates, or increasing rates of suicide amongst young people.

So in terms of some of the risk factors, what you can see here, and as I just said, a history of self-harm or previous suicide attempt is the strongest predictor of subsequent risk of suicide across the population and including in young people. I think what I always take away from this, is that as you've seen from the previous slide, a lot of these young people are seeking help but unfortunately what we know is when they do seek help they don't always get the help that they need.

So one of the take home messages for me always is if we're seeing young people presenting with self-harm or suicide risk to any clinical service, or in fact to any source of health, we need to be taking that behaviour seriously and then providing them with the support that they need. Whether that's clinical support or social support or what have you. We also know that the other most common risk factor for suicide and self-harm is mental disorder, most commonly depression, and that's often mediated by a sense of hopelessness.

You can see that there's all sorts of other traits here that are also associated with suicide risk and self-harm risk in young people, including behavioural things, like poor problem-solving skills, coping skills, exposure to suicide or suicidal behaviour in others. So that's that point I was making before about suicide clusters. Then there's issues around childhood adversity and lack of social support and conflict.

The thing that I would say about all of these, although I always feel mindful that I tend to kind of be presenting this picture of hopelessness, this kind of story of doom and gloom, but actually what all of these do is provide an opportunity for intervention. So we can intervene effectively when people present with self-harm. We can treat most mental health problems. We can kind of relieve the sense of hopelessness through good clinical care.

We can teach people and engage them in problem-solving skills, coping skills. We can help them manage some of the difficulties associated with some of these other factors. So it's not a story of doom and gloom – I think all of these risk factors actually present an opportunity for intervention.

So what might a framework for intervention or prevention look like in suicide prevention? So probably this framework will be familiar to most people. It's a framework that's commonly applied to mental health promotion and prevention and we use it a lot in suicide prevention as well.

So here what we've got, at the bottom of our pyramid are universal approaches that really target the general population regardless of risk. So the appeal of a universal intervention is that you can target a whole population group, so you can reach large numbers of people and potentially reduce suicide at that population level. Typical kind of suicide prevention approaches that sit in this universal category include things like restricting access to [means], which has been shown to be an effective suicide prevention strategy. Implementing media quidelines to promote safe communication about suicide.

Public education and media campaigns to raise awareness and promote help-seeking, and educational workshops, often delivered in school settings when we're talking about young people. Then as you move up your pyramid you get to these sort of selective interventions which start to target groups that might be at elevated risk of suicide. So they might be the people I was speaking about before, people who are presenting with mental health problems, or people who have been exposed to the suicide of a friend or family member.

So with these sorts of interventions, we're obviously reaching a smaller sector of the population, but our responses are getting a little bit targeted to those people who we know

might be at risk. These typically include screening or case detection kind of interventions and things like gatekeeper training to better equip people to identify and support people who might be at risk.

Then we get to the very top of our pyramid, this sort of pointy end, where we're delivering indicated interventions to those people who are already showing signs of being at risk of suicide. So they might be presenting with suicide attempt or suicidal ideation. These typically involve referral for clinical services, psychological and pharmacological treatment and so on.

In young people what we tend to see are a lot of these universal interventions are often delivered at school settings, as I was saying. They might be universal education programs delivered to cohorts of school students. They might be combined with screening interventions or case detection interventions to identify those young people who might be at risk. These are interventions that we've tested ourselves, and I'll talk a little bit more about, that have been shown to be safe and effective with young people.

As I said gatekeeper training is often seen to be effective, but I would argue strongly that it shouldn't just focus – typically this would focus on teachers or school wellbeing staff, but we should be certainly thinking about including other young people and family members in here. We do know that online treatment can be safe and effective when delivered to young people at risk of suicide. But what we also know is those interventions are most effective when delivered together and across settings.

So we did a big systematic review and meta-analysis a few years ago now which kind of underpins a lot of the work that we're doing in my team. We looked at interventions that were delivered across community settings. Here you can see that there were 16 of those studies, none of them were randomised controlled trials. But what we did see was that those multimodal, or place-based interventions, did seem to have positive effects. What we mean by multimodal is those sorts of interventions that were applying all the different strategies that I was talking about in that framework. They did appear to be having some effect on reduced suicide rates.

We looked at interventions in education and workplace settings and again found that school-based psychoeducation and screening interventions did appear to be showing promise. Many of the clinical interventions we looked at too also appeared to show promise in terms of reducing the frequency of both self-harm and suicidal ideation. But there were some gaps.

So there was no studies that we identified that were conducted in primary care settings. There were very few studies conducted in tertiary education or workplace settings. There were very few studies conducted online, which given the amount of time young people spend online, we thought was a bit counterintuitive. There were very few studies that were conducted with vulnerable populations, so I'm thinking now back to the groups that I mentioned at the very beginning. So First Nations young people, LGBTQI+ young people, and that also included young people on the autism spectrum disorder.

So very few studies targeting those populations. Very few studies were designed by or for young people. A lot of these studies were designed for adults, or a lot of the interventions being tested were designed for adults, and just being adapted or applied to young people.

So I'm going to give you a little bit of a snapshot, and it will be a whistle-stop tour, of some of the work we're doing across these different settings. So the first example I'm going to give you is some work we're doing in social media, so it sits in that universal category. It's targeting whole populations, regardless of risk, and really designed to mitigate some of the risks that are associated with talking about suicide on social media platforms but maximising some of the benefits.

So you can see here there are lots of benefits that young people talk about when it comes

to communicating about suicide online, the 24 hour/7 nature of social media – they find it accessible and appropriate and acceptable. You can read large numbers of young people quite quickly at relatively low costs. So lots of benefits. But we also know that there are some challenges and we know that there are certain types of communication that might occur on social media that might be unhelpful.

Particularly when it's exposure to harmful or negative content that might lead to that possibility of what we refer to as contagion, that might increase the risk of suicide and subsequent suicide death in clusters. But what we were hearing from young people, and the suicide prevention sector, were that positives outweighed the negatives when it did come to social media. So young people told us loud and clear that social media needed to be part of the suicide prevention landscape going forwards. So we worked, in partnership with young people and the suicide prevention professionals, to develop the chatsafe guidelines.

I suspect many of you are familiar with these now but they were developed using an expert, Delphi Expert Consensus process a few years ago. They really are designed to help young people feel better equipped to talk about suicide safely on social media platforms. They're designed around the ways young people told us they did use social media to talk about this subject. So there's sections here on how to share your own thoughts or feelings in a safe way. There's sections on how to respond to somebody else that might be suicidal. And sections on how to memorialise, or talk about somebody who's died by suicide, in a safe way.

The guidelines are freely available, so by all means have a look at them – freely available on the Orygen website. But we also know, even though they were quite innovative at that time and designed very much in partnership with young people, they're probably not that youth friendly. So we then worked with young people from across Australia to co-design a national social media campaign that we then rolled out in partnership with young people across various social media platforms.

So I think Snapchat was our best performing channel but Facebook, Instagram, YouTube, Twitter, Tumblr and so on. This just gives you a little bit of a flavour – I haven't got time to go into all the content now, but this gives you a bit of a flavour of what the Instagram page looks like, and what the content looks and feels like. But we were quite concerned, and this was some of the feedback we got from young people, very concerned to make sure that young people gained knowledge from the content. It wasn't just an awareness campaign; it was actually very much an education campaign.

We also did some evaluation of it, so you can see here it reached lots of young people — it reached about five million young people — so guidelines themselves and some of the associated resources we developed for adults have been downloaded over 100,000 times. The chatsafe intervention did appear to improve young people's willingness to intervene against suicide online, so help them feel better equipped and able to support their friends. It also helped improve their self-efficacy and confidence and safety when it came to online communication about suicide. They also reported being less likely to share harmful content — more likely to monitor their posts.

So that all presented a promising picture for the acceptability and potential impact of a universal social media campaign about suicide for young people. So we're currently doing a little bit of work now to update the guidelines and also to include self-harm. We're trialling them, so I presented just then some pilot data from a universal study, but we're able to launch a randomised control trial, and we'll also be testing them in more vulnerable populations as well. So thinking about using them as a selective and indicated intervention, and we're able to expand our work into school settings as well.

So that gives me the perfect segue to talk very quickly about some of our work in school settings, which is the study called the MAP Study which is a multimodal approach to preventing suicide in schools. So as I explained a little bit earlier, the systematic review we

did really showed that school-based studies seemed to be effective when we were combining things like large-scale psychoeducation programs with case detection programs to identify those students at risk. Then be able to refer them on and make sure those students got the treatment and care they needed.

So we piloted – we did a pilot study in Central Australia a few years ago now of the safeTALK program. So for those of you that don't know safeTALK, it's part of the LivingWorks suite of programs, it's like the baby sibling to ASIST training. It's a half-day workshop that's delivered by Lifeline trainers to Year 10 students, and it's really designed to help young people feel better able to identify suicide risk in themselves and their friends, and to respond.

So we partnered up with Lifeline Australia; they were delivering the training and we were evaluating it for them. We also developed a screening measure and built that into the evaluation, to make sure that delivering training to young people in school settings didn't cause harm. What we found was that it didn't 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.

As part of the screening measure, we were also able to identify quite a significant portion of young people who needed support, and we were able to refer them on to the school counsellor and the local headspace centre for help. So we piloted all of that a couple of years ago now. We also piloted an online cognitive behavioural therapy program called Reframe-IT, which we developed at Orygen and, as I say, we piloted this in a couple of different schools in our local area, in North-West Melbourne, and again found positive effects.

So I can't go into the details but it's an eight module 15 minute video based CBT program. What we found here was that there were no negative effects, again as per before, and we found that suicidal ideation, depressive symptoms and hopelessness decreased as a result of receiving the intervention. Problem-solving and coping skills increased.

So, aligned with what the evidence is telling us is best practice, we've now combined all of those interventions into one large-scale study where again we've partnered up with Lifeline and LivingWorks, we're delivery safeTALK training to all Year 10 students, or we're offering it to all Year 10 students in schools across the North-West Melbourne. We'll be screening all of those students to identify any students at risk and referring them on to make sure they get the help that they need. We'll also be then feeding those young people, who are at risk and who consent, into a trial of the Reframe-IT program that will be delivered to around 200 school students across the region.

In addition to that, and because this is a really important part of the puzzle, we're also offering ASIST training for nominated school staff members and start training to parents of students, and we've trained about 200 parents so far. So taking a very holistic approach to building capacity across school settings in our region. Again, that was a whistle-stop tour of what we're doing in schools, and I'm obviously happy to take any questions about that if people have them.

But I just wanted to sort of start to wrap-up a little bit by talking just briefly about a piece of work that one of my post-docs has been supporting a Master student to do. Which is a qualitative study, looking at their experience of suicidal — of feeling suicidal and self-harm with young autistic people who have come through Orygen's clinical services. So this is sort of very hot off the press. Linda's still writing up her thesis as we speak.

But the aims of this study were really again to — you know we were hearing very much from our clinicians that this was a population who were very much in need of support and perhaps where suicidal behaviour and self-harm looked and felt a little bit different to other young people that were coming through the clinics. So we aimed to set out to examine what young people's experience was of these behaviours or these feelings, the relationship

between suicidal ideation and self-harm. Their experience of seeking help, and whether those experiences were influenced by gender, either their own gender or the clinician's gender.

So we did some qualitative interviews with five young people who had come through our clinic. I'll just give you a real snapshot of some of the high-level findings. So what you can see here is some of – these were some of the key themes that emerged from the study, that interpersonal and intrapersonal understanding facilitated that connection to both the individual themselves, and to others, including their clinician.

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 population.

The other high-level theme that Linda identified was this duality of relating to others. The connection within that therapeutic relationship really tended to be slow and complex, and really tended to impact on the therapeutic experience. So some of the takeaways from this study were that suicide and self-harm were really used as emotion-regulation tools to escape really unbearable situations. There's this idea of kind of really increasing interpersonal and intrapersonal understanding could protect against self-harm and suicide.

We really need to be flexible and think about what the needs are of young autistic people when we're delivering services or mental health based interventions across our clinics. We really need to be including these young people in co-designing what some of the solutions might be for them.

I think that brings me just to the final point I want to make, which is about youth involvement in suicide research. So look, I think we've done a really good job in suicide prevention over recent years, of involving people with lived experience in the sector. I think probably more and more across mental health services, we're also doing a good job of partnering up with young people when we're co-designing services and mental health interventions. But I don't know that we've done a very good job of partnering with young people when we've been doing suicide prevention research. I think that that would extent to young people on the autism spectrum.

So we're doing some work now where we're trying to redress that. We think that young people have got a lot to contribute and I think as long as we put the correct safety mechanisms in place, and look after their wellbeing, we think that actually it's critical that we are partnering up in a better way with young people going forward. I also think that – I showed you at the very beginning some of those graphs that were showing these increasing rates of suicide and self-harm in young people – we've had a lot of investment over recent years in suicide prevention efforts, but I'm not sure that they're really hitting the mark with young people. I suspect that's because we're not partnering with them in designing the solutions and strategies for them.

So in this study here, we're really aiming to develop and distribute a set of best practice guidelines, to help guide youth partnerships in suicide prevention research. We're again using a Delphi Expert Consensus methodology and we'll have a couple of panels of experts which will include suicide researchers and young people. Hopefully those activities will lead to a suite of outputs, including guidelines and supporting resources, partly for researchers to help us feel better equipped or have some guidelines or frameworks around how we might include young people as partners in our research.

We'll have some guidance for young people around what they should expect, and how to help them advocate for themselves when it comes to partnering up in research projects. And some guidance for ethics committees who I think get terribly nervous about the wellbeing of young people when it comes to suicide prevention research. So hopefully that will be reassuring for them as well.

We hope that those guidelines will really help facilitate the design of more effective and youth-friendly suicide prevention activities, or research, and ultimately achieve better outcomes for young people. I just left these two studies here, just because these are some examples from our work of how poorly we do partner with young people when it comes to suicide prevention research, so far.

So just to wrap all of that up, as I said unfortunately rates of suicide and self-harm are increasing here in Australia. They're also increasing elsewhere in the world. So we're not on our own with this problem, but we do need to do a better job of redressing it. Evidence does suggest that there's a number of interventions that can be effective when it comes to reducing risk, but we do need more high-quality studies, and possibly a more systematic approach and strategic approach to suicide research. So really investing where we need research to be conducted.

I think interventions really need to be delivered across settings, and as I've said, universal selected and indicated interventions, delivered in combination, seem to yield the best results. But we do know that there are a lot of settings and a lot of populations that are so far underserved when it comes to suicide prevention research. So I do think we need to be filling some of those gaps.

We've also learnt that it can be safe and beneficial to involve young people as active partners in suicide prevention, and so young people do need to be part of a solution going forward. I think if we can do that, we will start to do a better job of reducing some of the rates of suicide and self-harm that we're currently seeing.

And on that, I would say thank you very much for your attention. I'm sorry that was a bit of a whistle-stop tour. But I'd like to, as I say, say thank you for listening. Thank you very much to our funders, and also thank you to all of the young people that have taken part in all of our studies.

Thank you.



Transcript Keynote Speech: Professor Phil Batterham " (ANU, Canberra), PhD, Centre for Mental Health Research.

# "Understanding and preventing suicidal behaviour in the general population."

Hi, my name is Phil Batterham, I'm from the Australian National University and today I'm presenting on [Ngunnawal] country and I pay my respects to Elders past, present and emerging. I'm going to be talking today about research we've done to better understand and to prevent suicidal behaviour in the general community. A brief summary of what I'm going to talk about today, first I'm going to give a bit of background about suicide in Australia, defining what suicidal distress is and what it looks like.

I'm talking a bit about some suicide statistics, some of the risk factors for suicide. I'm then going to be talking about some of the research we've done to better understand suicidal behaviour in the adult population and looking at the specific theory around why people engaging in suicidal behaviour. Then I'll talk a bit about preventing suicidal behaviour which is a fairly broad topic but I'm going to be focusing specifically on research we've done around stigma and its relationship to help-seeking among people who are experiencing suicidal thoughts and behaviours and then I'll finish with some conclusions.

Starting with some background. Suicidal distress occurs on a spectrum, so you can see on the right here there's people might encounter suicidal thinking or suicidal ideation, they might progress to having a suicidal plan or preparation for a suicide attempt, and then suicidal behaviour such as suicide attempts, and unfortunately for about 3000 Australians per year, ending with suicidal death. People don't always move along this spectrum in the sequence shown here, there are some people who don't plan suicide attempt but do have a suicide attempt, so people can move back and forth along this spectrum.

There are a range of different indications of suicidal thinking and suicidal behaviour along the spectrum from suicidal thoughts, and this can be passive thoughts thinking about death or more active thoughts thinking about suicide, all the way down to suicidal behaviour. It's important to note that there are different risk factors that influence each of these things, so there are a different range of risk factors that influence whether somebody develops suicidal thinking compared to those risk factors that are associated with suicide attempt.

There are some risk factors obviously that overlap between those two things, but there are also a number of differences there. As you can see here, it's a bit like an iceberg. At the tip of the iceberg, what we see in the community and in health services are suicide deaths. Those are fairly accessible in terms of how many there are per year. There are about 3000 suicide attempts per year and this is tracked through coronial reports. It's not always easy to ascertain whether a death has been suicide or not, so for that reason it sometimes takes a while to ascertain how many suicide deaths there have been in a year.

In terms of suicide attempts, so some of these occur in the community so they're not seen in medical settings, they're not - people don't always end up in hospital or end up at their GP when they do attempt suicide, but we do know that there's somewhere between 60,000 and 80,000 suicide attempts per year in Australia. Then further down we see suicidal ideation much more common, approximately 600,000 people per year in Australia experience suicidal ideation, although again, depending on how you define suicidal ideation, those numbers can vary quite a bit.

What we see in the community are suicide deaths and medically treated suicide attempts. They're quite countable because we know how many people present to hospital and how many people die. It's much harder to get a handle on how many people attempt suicide in the community and how many people experience suicidal thoughts. So these data come from the National Survey for Mental Health and Wellbeing, which was last conducted in 2007 in Australia.

In terms of suicide deaths, we can see there's the pattern over the past 15 years is shown in this graph here. You can see from this that males have a much higher rate of suicide deaths than females. So about 75 per cent of suicide deaths are accounted for by males, but if you look at suicide attempts and suicidal ideation, the prevalence is actually higher in females so we see a reversal of this trend. But these are data for Australia so it's the annual rate of suicide deaths per 100,000 people.

For males, you can see that's fluctuated between about 15 and 20 per 100,000 per males - annual suicide deaths per 100,000 males over the last 15 years, and for females that number has been around five deaths per 100,000 females annually over the last 15 years. You can see there's a slight upwards trend that follows from, back in the 1990s the levels were higher than they are currently. That decreased down to around - in 2000 but has been - had a slight steady increase since then.

The age groups for the highest rates of suicide death are those aged between 30 and 34, and 40 and 44. These are around 18 per 100,000 of the population so it does vary over age groups. But if you look at the proportion of deaths accounted for by suicide, that's highest in the 20 to 24 year old age group, where over one-third of all deaths are due to suicide. It's partly because people aged in - who are younger, are younger adults, don't tend to die from other causes as often, such as heart attacks or cancer, but we do see a large proportion of suicides in younger adults, a large proportion of deaths being suicide in younger adults. Suicide is the most common cause of death for Australians aged 15 to 44 years old.

My focus today is talking mostly about data from the general population and most of my work is in adults - looking at suicide risk in adults. I've also tried to draw a little bit on some of the implications for suicidal distress in people with autism, although that's not my specialty area. I'm going to talk a bit more about understanding suicidal behaviour and why suicidal behaviour happens. It's a very complex picture, there's a whole constellation of risk factors that influence whether somebody experiences suicidal thoughts or engages in a suicide attempt, and I've roughly clustered those in here.

There are social factors that influence suicidal behaviour such as isolation, and also relationship breakdown, which is also a life event - a difficult life event. Other life events such as trauma, violence, unemployment or financial pressures can also influence suicidal thinking and suicidal behaviours. There are demographic features, we've already shown you that age and gender are associated with suicidal behaviours. There are a range of psychological factors that influence suicidal thinking in particular, but also suicidal behaviour.

So things like rumination, which is not being able to stop thinking about the same things over and over again, and mastery, feeling like you can enact change in your life, as well as personality factors and feelings of hopelessness that things won't change. Obviously there's a strong mental health component in suicidal behaviour, not just confined to depression but also to anxiety, other mood disorders, as well as substance use and psychosis. Physical health problems are also - may be associated with suicidal behaviour, as is limited access to health services.

Previous suicidal experiences is one of the strongest risk factors for suicidal behaviour, so having previous suicidal ideation not surprisingly, and having previous history of suicide

attempt greatly increases the risk of future suicidal behaviour. It's very complex trying to understand why people attempt suicide. There are a range of different interacting risk factors. Suicidal ideation is much more common that suicide attempt, as I've shown you with that iceberg picture. It should be noted that most people with suicidal thoughts don't go on to have a suicide attempt, so even if they have a range of risk factors such as previous suicide attempt, in most cases people won't go on to die by suicide.

It's important to develop better theories and better understanding though, of the process which therefore lead people from going from having thoughts about suicide to action it and enacting a suicide attempt. So a lot of the theory and research in the area is trying to understand that process of why people go from thinking about suicide to then going and attempting suicide. One of the more prominent theories over the past 10 to 20 years has been the interpersonal psychological theory of suicidal behaviour.

This was developed by Thomas Joiner, who's a psychologist and researcher from Florida. He suggested that there are these interpersonal risk factors which have a very psychological component as well that influence whether somebody's going to experience suicidal thoughts, and because he's a psychologist he liked to use big names for these constructs that he wanted to focus on in his theory. One of these is thwarted belongingness, which is a sense of isolation or an unmet need to connect with broader community, and the other is perceived burdensomeness, which is this idea that you're a burden on others, that you don't feel valued by other people or that you're a liability to other people.

His theory was that people who had both of these characteristics or feelings, thwarted belongingness and perceived burdensomeness, were much more likely to have a desire for suicide or suicidal thoughts. However, it's only in the presence of this third construct which is called suicide capability or capability for suicide that is more likely to see a suicide attempt occurring. You can this capture that idea that suicide attempts are much less likely than suicidal ideation because it's only that small sliver of the circle where people have all three of these things - thwarted belongingness, perceived burdensomeness and suicide capability that you are actually likely to see somebody wanting to - having a suicide attempt.

Suicide capability arises, according to Thomas Joiner, from a mixture of increased pain tolerance and a low fear of death, among other things. This theory actually fits quite nicely in explaining why there are so many different risk factors for suicide and potentially how these interpersonal constructs might influence suicidal behaviour. So we've looked at this in a few research articles and a few different studies to look at where these different risk factors for suicide fit in to the interpersonal psychological theory, and we found that things like relationship breakdown, isolation, perceived lack of social support, not surprisingly, these things are closely associated with thwarted belongingness.

Whereas some of the psychosocial risk factors relate to financial pressure and then health problems, substance use and some of those psychological variables such as rumination or hopelessness, are more associated with perceived burdensomeness, so feeling like you're a burden on other people. Then in terms of capability for suicide, there's a range of other factors that might fit into that, such as exposure to trauma or violence and being in a high-risk occupation, and males tend to have higher levels of capability for suicide than females.

You might also notice there that high mastery is associated with higher capability for suicide whereas low mastery is associated with higher perceived burdensomeness. So there might be these opponent or different processes that happen with some of these psychological constructs where in some cases that can be protective against suicide, and in other cases they can be risk factors for increased risk of suicidal thoughts or suicidal behaviours. This is an interesting model and it's useful for explaining in some cases why people might engage in suicidal behaviour.

We've actually looked at the evidence for this theory in a large systematic review that was

published back in 2016 led by one of my PhD students, [Jennifer Maher]. She looked at the evidence for each of these constructs and whether the interactions between constructs were associated with the outcomes of ideation attempt along the lines of what the model or the theory would hypothesize, and she actually found there wasn't a whole lot of evidence for the effects of thwarted belongingness by itself on suicidal ideation. Only 40 per cent of the studies found a significant relationship between thwarted belongingness and ideation.

The evidence for perceived burdensomeness was much more compelling. So you can see there's almost 70 studies looking at the effects of perceived burdensomeness on suicidal thinking, and 83 per cent of those found a significant relationship there, so very strong and consistent relationships between perceived burdensomeness and suicidal ideation. When you look at capability for suicide, only about nine studies had looked at that and about half of them found that capability was associated with a suicide attempt.

When you look at that critical interaction between thwarted belongingness and perceived burdensomeness on suicidal ideation, there haven't actually been many studies that have fully tested the theory, because the idea is that you need both of these to be present for ideation to occur. From the 12 studies that have looked at that back in 2016, we found that about two-thirds of those studies found the significant interaction effect, suggesting that both thwarted belongingness and perceived burdensomeness needed to be present for a suicidal ideation to occur.

It's actually quite hard to find a three-way interaction between thwarted belongingness, perceived burdensomeness and capability or required capability for suicide, which is what the theory proposes, is that it's only when all three of these occurred at a suicidal attempt will happen. So there were only about eight studies or seven studies that looked at this three-way interaction, this relationship, and fewer than half of those studies found a significant relationship. That's partly because you need a really large study to find that effect but it also suggests there might be some issues with the theory with how these constructs are measured and with how the constructs relate to suicidal behaviours and suicidal thoughts.

I'd just like to briefly touch on some research that's been conducted not by myself but by other groups in the UK, looking at whether interpersonal risk is associated with suicide in people with autism. This study by [Pelton] and colleagues is quite recent - it was published last year - found that people with autism experienced higher levels of thwarted loneliness and perceived burdensomeness. However, that interaction effect which I was just talking about was only associated with suicidal ideation in the group without autism, it had no significant association among those with autism.

So it suggests that maybe these interpersonal risk factors might be less pernicious among people with autism. However, autistic traits also did influence suicidal ideation through their connection with these interpersonal risk factors of burdensomeness and belongingness. The authors from this study suggested that promoting self-worth and social inclusion may be important approaches for suicide prevention and this is a case for people with autism as well as people without autism.

There are a range of other theories, I won't go into detail about these other theories but they all have a similar component to them, is that they're trying to - they suggest that there are different factors - so I've got them in blue and purple and orange here - different factors associated with going from being healthy to experiencing distress and defeat, and then going from that to going - transitioning into suicidal ideation and then transitioning from suicidal ideation to attempt. There are different risk factors that underlie those different transitions over time.

A couple of the prominent theories are listed there, the integrated motivational-volitional model, which is a very - another long term for a model by Rory O'Connor and colleagues, and a couple of other theories there which have a similar focus on trying to differentiate between the processes involved with people who develop suicidal thoughts compared to those who develop suicide attempt.

Summarising this research. There are a range of diverse risk factors for suicide and there are different processes that underlie the development of suicidal thinking versus suicide attempts, but a consistent finding in the literature is that unmet needs for social connection, as well as not feeling valued, may explain suicidal distress in many people. In the next section, I'm going to talk a bit about what we can do to prevent suicidal behaviour. So first a brief summary of some of the approaches that have been shown to be highly effective in previous research.

Firstly, access to treatment. Obviously psychological therapies and anti-depressants have been shown to markedly reduce risk for suicide. This work comes from - this summary comes from a study which looked at suicide deaths specifically, and they found that based on all the literature to date there is evidence that psychological therapy and anti-depressants are effective for reducing suicide deaths.

Similarly, means restriction, so restricting people's access to the common methods of suicide reduces suicidal deaths and suicide behaviours.

Prevention training for frontline health workers particularly, including GPs, has a positive effect on reducing suicide. There's some evidence that school based programs that support young people through education and connection to trusted adults can reduce suicidal behaviour in young people as well.

Continuity of care after a suicide attempt. After people have a suicide attempt, that's a really high-risk time. There's much higher risk of suicidal behaviour after a suicide crisis, so ensuring that people after they have a suicide attempt go into an emergency department or see their GP. It's important that they have strong continuity of care and are appropriate supported after that suicide attempt because all too often in hospital departments, in emergency departments, they just focus primarily on the physical needs of people who have attempted suicide and less on connecting and to care and their mental health needs.

There's a range of other possibilities which have been shown to, in many studies, reduce ideation and potentially reduce suicide attempts, but there's limited evidence for their effect on suicide deaths. Things like screening for suicide thinking - suicidal thinking, educational programs for the general public, the incorporation of media guidelines so that reporting of suicide in the media is responsible and follows appropriate guidelines to reduce the likelihood of copycat suicide attempts.

Gatekeeper training, so training key people within an organisation to support people who might be suicidal. Then internet intervention, so it's only over the last 10/15 years that internet-based therapies have been made available and tested in terms of whether they reduce suicidal thinking, and there's mixed evidence for this. I've been involved in a number of trials looking at the effects of internet programs, internet-based therapy on suicidal ideation, and it's difficult to demonstrate that effect, though there is some evidence that they can be beneficial for reducing suicidal ideation, and a lot of evidence that they can reduce depression and anxiety symptoms as well.

I'm going to focus a bit on the access to treatment side of things, how people engage with treatment and some of the work we've done around stigma. There are a number of reasons that people find it difficult to access care. There are a number of structural barriers such as the time and the cost it takes to engage in professional care, the availability of services and access to transport, people in rural areas find it more difficult to access care. There's also a range of personal barriers, such as previous experience, which might be negative experience of health services. Perceived need, whether somebody feels like they need to have professional support. Self-reliance, which is the idea that you can take care of problems by yourself, which, a certain level of self-reliance is helpful that you can take care of things by yourself, but very high levels of self-reliance may mean that people don't go and seek help

when they need it.

Two other areas are stigma and literacy, which is an area where we've done quite a bit of research. Stigma refers to negative attitudes or behaviours towards a group of people which is based on negative stereotypes, and we've looked at suicide stigma specifically in our research. Mental health literacy is public knowledge so it's basically just knowledge, knowing about facts about things like risk factors, causes, signs or symptoms and treatments for mental health problems. That's also been applied to understanding about suicide prevention, so knowledge about suicide prevention.

A few years ago we developed the Stigma of Suicide Scale. This is the short form of the Stigma of Suicide Scale. It's got 16 items which measure a range of different attitudes. There's stigma - items about stigma, there's items about attribution of suicide to isolation and there's items about the glorification of suicide. People are asked to rate each of these items on a five point scale based on how much they agree with whether a person who dies by suicide meets these descriptors, and in that way we can get a brief and fairly useful indication of how much stigma they have and how much attitudes they have around isolation and glorification towards suicide.

We also developed the Literacy of Suicide Scale to measure mental health literacy related to suicide prevention. There's 12 items in the short form of this scale. You can see here those items clustered around risk factors for suicide, the nature of suicidality and some of the signs or symptoms of suicidal behaviour and treatments or preventions for suicidal behaviour. So the ones in yellow here are the ones which are false, and the ones in white are classified as true.

Our research has shown that high levels of stigma and low levels of suicide literacy lead to both poorer attitudes to professional services and lower intentions of seeking help. So high stigma and low literacy can be quite pernicious with people being less likely to engage in professional help-seeking. There's been a bit of research as well around service use in people with autism specifically. Less stigma and less social comparison are associated with greater levels of service use. So as we see in suicidality, lower stigma is good in terms of help-seeking and the authors of this study suggest 10there are benefits in improving public attitudes, both towards people with mental ill health and towards people with autism, and overall, as with the suicide literature, reducing barriers to seeking professional help does lead to better health outcomes overall.

Wrapping up now with some of the conclusions of my talk today. Firstly, take home messages - five take home messages. Firstly, there are many factors underlying suicide, it's a complex area. It's important to differentiate between suicidal thoughts and suicidal behaviours. There are different factors underlying those two different things. I went over the interpersonal psychological theory and some of the evidence for that theory that we've shown from our research, and that suggests that there's an unmet need for social connection which underlies a lot of suicidal distress.

I summarise some of the effective approaches to preventing suicide and there are many of those, some of which need more evidence, but there's a lot of effective approaches, and it's like that a combination of different approaches is needed to prevent suicide in the community. Getting professional support early is important and our research shows that, but there are a number of different influences around whether people do seek help, and these include suicide stigma and suicide literacy.

So I'd like to thank my many collaborators in the research that I've presented today, and thank you for the Society for inviting me to talk today, particularly to Darren and I acknowledge my funding from the National Health and Medical Research Council. I'm happy to take any questions.

Poster title Self-determination as a mediator between autism traits and quality of life

**Author(s)** Helen Andrews BPsyScHons<sup>1</sup>, Dr Darren Hedley<sup>1</sup>, and Dr Simon Bury<sup>1</sup>

**Author affiliation(s)** 1 Olga Tennison Autism Research Centre (OTARC), La Trobe University

Presenting author Helen Andrews - <u>Helen.Andrews@latrobe.edu.au</u>

Conflict(s) of interest N/A

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supported by a Suicide Prevention Australia National Suicide Prevention Re-

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Lay abstract

Autistic people continue to report, on average, lower quality of life (QoL) than non-autistic people. Self-determination Theory may partly explain this disparity. Self-determination (SD) is loosely defined as being in control of one's life and develops through satisfaction of three psychological needs: autonomy (perceived free choice), competence (perceived ability to succeed) and relatedness (perceived connectedness to others). Autistic people tend to report lower SD than non-autistic people. This study found that SD partly explains the relationship between autism traits and quality of life. Supporting development of self-deter-

mination may lead to improved QoL for autistic people.

Abstract Background:

Autistic people report poorer quality of life (QoL) than non-autistic people. One factor associated with QoL is self-determination (SD), which is defined as experiencing causal agency and results from satisfaction of three psychological needs: autonomy (perceived free choice), competence (perceived ability to succeed) and relatedness (perceived connectedness to others). SD develops within social contexts and difficulty in this area is a diagnostic criterion for autism. Further, autistic people tend to report lower self-determination than non-autistic people and autism traits are normally distributed throughout the population, indicating QoL implications for the broader autism phenotype.

**Objectives:** 

This study tested a mediation model where self-determination (represented by satisfaction of the psychological needs for autonomy/competence/relatedness) mediated the relationship between autism traits and four domains of QoL (physical/psychological/social/environmental).

Methods:

General population participants (n = 262) 18 to 71 years ( $M_{AGE} = 37.6$ , SD = 11.92 years; 167 women) completed online questionnaires. Results were analysed using the SPSS PROCESS macro (Model 4).

Results:

Satisfying the need for competence mediated the relationships between AT and all QoL domains; relatedness mediated between AT and environmental/social/psychological QoL; and autonomy mediated between AT and physical/environment QoL, indicating AT may impact QoL through thwarting of psychological needs.

**Conclusions:** 

As self-determination was found to mediate between autism traits and quality of life, Self-determination Theory may present an opportunity to discover some of the mechanisms underlying quality of life for autistic people, and to design tailored supports and interventions to empower autistic people to improve their self-determination and quality of life.

Poster title "I Found at Times I Wasn't Being Heard": The Experiences of Autistic Adults in

Working with Psychologists in Australia.

**Author(s)** Rebekah Benn<sup>1</sup>, Rebecca Flower<sup>2</sup>, PhD, & Rachel Jellett PhD<sup>1</sup>

**Author affiliation(s)** Olga Tennison Autism Research Centre, School of Psychology and Public

Health, La Trobe University, Vic, Australia

<sup>2</sup>Department of Psychology and Counselling, School of Psychology and Public

Health, La Trobe University, Vic, Australia

Presenting author

 $Rebekah\ Benn-\underline{rebekahbenn7@gmail.com}$ 

Conflict(s) of interest

N/A

Funding Lay abstract School of Psychology and Public Health La Trobe University

Co-occurring mental health conditions are disproportionately high among autistic adults. Compared to non-autistic adults' autistic people have increased rates of suicide attempts, psychiatric disorders and, experience several barriers accessing psychological services. This research conducted interviews to understand the experiences of autistic adults in working with psychologists in Australia. Overall, participants provided a consistent narrative, indicating that they experienced challenges accessing and benefiting from psychological services and felt their mental health care needs were not met.

Abstract Background:

Autistic adults are more likely to experience several mental health conditions compared to non-autistic adults. When accessing psychological treatment, autistic adults' encounter many barriers, negatively impacting their experiences and have reported their needs are not being met. To our knowledge, no research has investigated the experiences of autistic adults when interacting with psychologists in Australia.

# Objectives:

The study aimed to explore the experience of autistic adults in working with psychologists in Australia. We hoped to identify a) what autistic people feel that psychologists are doing well and areas for improvement when working with autistic clients, and b) what psychologists need to know about autism to work with autistic clients effectively

# Methods:

This qualitative study used semi-structured interviews developed in collaboration with autistic advisors.

# Results:

Reflexive thematic analysis identified five primary themes across the data. (1) What you see is not what you get, (2) Not being heard and validated, (3) The importance of building rapport, (4) How psychologists help autistic people and (5) Autistic people need support, not fixing.

#### **Conclusions:**

Participants in this study provided a consistent narrative of challenges in accessing and working with psychologists. Together, these findings imply a need for improvement in what psychologists know about autism to work with autistic clients effectively.

Poster title Personal Wellbeing and Stress in Autistic Adults: Before and During COVID-19

**Author(s)** Claire M. Brown<sup>1</sup>, Darren Hedley PhD<sup>2</sup>, Matthew Fuller-Tyszkiewicz PhD<sup>1</sup>, Merri-

lyn Hooley PhD1 & Mark A. Stokes PhD1

**Author affiliation(s)** ¹Deakin University, School of Psychology, Faculty of Health. ²Olga Tennison

Autism Research Centre, School of Psychology and Public Health, La Trobe

University.

Presenting author Claire Brown - Claire.brown@deakin.edu.au

Conflict(s) of interest N/A

Lay abstract

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Prevention Research fellowship.

During 2020, the COVID-19 lockdown restrictions changed most people's day-to-day life. We asked autistic and non-autistic adults about their wellbeing, and measured symptoms of stress each month from June to November 2020. We then compared this to information we collected before the pandemic. We found that autistic adults experienced more stress, and worse personal wellbeing than non-autistic adults. However, we also found that personal wellbeing and stress levels were better than in 2019, before the pandemic began. This helps us to understand the types of support that autistic adults will benefit from to reduce

stress and improve wellbeing.

Abstract Background:

In 2020, COVID-19 restrictions introduced by the Victorian and Australian governments impacted most people's typical daily life. It is currently unclear what implications restrictions had for the mental health and wellbeing of Autistic adults, who are known to experience disproportionately high rates of mental health concerns.

**Objectives:** 

We aimed to measure mental health and wellbeing across the Victorian second wave of the COVID-19 pandemic and compared these data to 2019 baseline, pre-COVID levels.

Methods:

We recruited 391 Australian adults, comprised of 199 autistic (Mage=43.71, SD=14.40) and 192 non-autistic participants (Mage=38.38, SD=9.92). Severity of depression, anxiety, stress, eating disorder symptoms (DASS-21 & EDE-QS) and personal wellbeing (PWI) data were collected in two discrete phases. Phase 1: 2019 baseline levels; and Phase 2: at monthly intervals from June to November 2020.

Results

We found that autistic traits were associated with lower personal wellbeing and increased mental health symptom severity. However, relative to 2019 baseline levels, aggregate severity of depression, anxiety and stress decreased among autistic adults across the Victorian second wave of the COVID-19 pandemic in Australia. We also found that stress significantly mediated the relationship between autistic traits and personal wellbeing at all time points.

Conclusions:

The results show personal wellbeing and mental health symptoms were not worsened by the government restrictions. In fact, they appear to have had a somewhat protective effect. These results provide some insight into the difficulty autistic individuals experience in many daily situations, and suggest paths toward supportive measures that may be undertaken in future.

Poster title Utilising lived experience and co-design to develop autism specific work-

**Author(s)** Simon M. Bury<sup>1</sup>, Susan M. Hayward<sup>1</sup>, Cheryl Dissanayake<sup>1</sup>, & Darren Hedley<sup>1</sup>

Author affiliation(s)

<sup>1</sup> Olga Tennison Autism Research Centre, La Trobe University, Melbourne, Australia

Presenting author Simon Bury - s.bury@latrobe.edu.au

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Bank, and Untapped Holdings.

To better support the mental health of autistic employees, autism specific workplace mental health training was developed, with targeted content for supervisors, colleagues, and autistic employees. This poster describes the process of consultations and co-design with autistic employees with lived experience of mental health, that better ensured the usefulness and appropriateness of the training package. Autistic people were included at the design stage and reviewing each of the modules. Amongst other important improvements, consultation led to improvements to the language of the training (e.g., more strengths-based language), greater emphasis on creating autism friendly

work environments, as well improvement to structure.

Abstract Background:

Lav abstract

Autistic adults have poorer employment and well-being outcomes. Importantly, workplace well-being is integral for sustainable employment. Our recent research on the DXC Dandelion Program reported positive outcomes from employment for autistic employees (e.g., sense of purpose). However, expected improvements in mental well-being were not observed (Hedley et al., 2019), and support staff were unable to identify autism specific mental health resources. To fill this gap, we developed a mental health training toolkit (Bury et al., 2020) drawing on psychoeducation approaches to support general (Kitchener & Jorm, 2002) and workplace mental health (Gayed et al., 2018), and designed to upskill supervisors, colleagues, and autistic employees to improve mental well-being at work.

**Objectives:** 

To detail the stakeholder and co-design processes, as well as their impact on the development of a workplace autism well-being toolkit.

Methods:

Amongst a range of stakeholders (e.g., employers), autistic workers with lived experience of mental health challenges were recruited to help design and refine content for the toolkit. Involvement was at the content planning stage, and through review of all modules, utilising various communication techniques (e.g., zoom, survey, chat).

Results:

Co-design practices resulted in changes to language and clarity; a focus on strength-based language; greater emphasis on creating autism friendly environments (e.g., diversity, culture); and changes in structure to ensure equal access to tailored stakeholder strategies.

Conclusions:

Balanced within the broader stakeholder engagement, co-design led to significant improvements in the content and structure of the toolkit. Future research will test the effectiveness of this training within workplaces.

Poster title Treating disruptive behaviors in toddlers with autism traits using Parent-Child Interaction Therapy for Toddlers: A Case Study

Sara Cibralic<sup>1,2</sup>, Jane Kohlhoff<sup>1,2</sup>, Nancy Wallace <sup>1,2</sup>, Catherine McMahon<sup>3</sup>, &

Valsamma Eapen<sup>1,4</sup>

Author affiliation(s) 

1 School of Psychiatry, University of New South Wales, Hospital Rd, Randwick,

NSW 2031, Australia

<sup>2</sup> Karitane, 138-150 The Horsley Dr, Carramar NSW 2163, Australia

<sup>3</sup> Centre for Emotional Health, Psychology Department, Level 7, Room 715, C3A Building Macquarie University, North Ryde, NSW 2109, Australia

<sup>4</sup>Academic Unit of Child Psychiatry South West Sydney & Ingham Institute, Liverpool Hospital, Elizabeth Street, Liverpool, NSW 2170, Australia

Presenting author Conflict(s) of interest

Sara Cibralic, <u>s.cibralic@unsw.edu.au</u>

**Funding** 

Author(s)

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Lay abstract

Behaviours such as aggression, severe tantrums, and head-banging are common in children with autism traits and are often one of the first reasons that parents of children with autism traits seek out assessment and intervention services. Often parents seek professional assistance well before an autism diagnosis is received. This study assessed the effectiveness and intervention known as Parent-Child Interaction Therapy for Toddlers (PCIT-T) in reducing such behaviours in a young child with autism traits.

**Abstract** 

#### Background:

N/A

Externalising behaviors are often the first reason that parents of children on the autism spectrum disorder seek professional assessment and treatment. Parent-Child Interaction Therapy for Toddlers (PCIT-T) is an attachment and behavioural based parent training program targeted at reducing externalising behaviours in toddlers aged 12 to 24 months by improving the parent-child attachment relationship and child and parent emotion regulation

# **Objectives:**

This study assessed the effectiveness of PCIT-T in improving emotional regulation and the parent-child attachment relationship and reducing externalising behaviour in a child presenting with moderate-to-severe autism traits, low intellectual and adaptive functioning, externalising behaviours within the clinical range, and a disorganised/insecure mother-child attachment relationship.

# Methods:

The intervention took place over a 12-week period and focused on improving positive parenting skills, parent emotional regulation, and child emotional regulation.

#### Results:

Study results provide preliminary support for the use of PCIT-T in treating externalising behaviour, improving the parent-child attachment relationship and child emotional regulation in a toddler with autism traits.

#### **Conclusions:**

These results indicate that PCIT-T can be beneficial for children with autism traits and externalising behaviour, however, further research with a larger sample size is needed to strength these findings.

Poster title Sensory Processing: From Autism to Mental Health

Author(s) Laurence Cobbaert<sup>1</sup>, Ruth Minkov<sup>2</sup>, & Matthew Sellen<sup>3</sup> Author affiliation(s) <sup>1</sup> School of Psychiatry, University of New South Wales,

<sup>2</sup> School of Psychological Sciences, University of Melbourne,

<sup>3</sup> The Centre for Neurodivergence, Canberra

Presenting author Laurence Cobbaert - <a href="mailto:l.cobbaert@unsw.edu.au">l.cobbaert@unsw.edu.au</a>

Conflict(s) of interest N/A **Funding** N/A

Lay abstract Sensory processing is an important feature of autism. Growing evidence is also showing that sensory processing is a factor involved in mental health conditions such as anxiety and depression. As autistic researchers and clinicians, we recommend that sensory processing be taken into consideration in

inpatient mental healthcare facilities.

A literature review was undertaken to explore relationships between autism, Abstract sensory processing, and mental health, and to examine existing evidence for sensory-informed care in inpatient mental healthcare facilities.

> There is mounting evidence highlighting the key role of sensory processing in cognitive processes and psychological phenomena. Indeed, sensory processing patterns have been associated with creativity and emotional lability, as well as a range of mental health conditions, including depression, anxiety, and psychosis. While sensory environments influence everyone's wellbeing, autistics are more vulnerable to experiencing distress due to over or under stimulation. This is due to an atypical sensory processing pattern at baseline, involving both interoception and exteroception. As a result, autistics vitally need to engage alternatively in sensory-seeking and sensory-avoiding activities according to contextual factors. This allows for self-regulation of emotions, sensory overwhelm, and attention. Recent investigations have also demonstrated the risk reduction and de-escalation benefits of accommodating sensory needs. Unfortunately, inpatient mental health settings are not appropriately designed to accommodate sensory needs. Mental health clinicians also often lack awareness in relation to the importance of sensory processing in emotional self-regulation, which can manifest in the provision of counterproductive interventions. As autistic researchers, we believe that all mental health patients should have a sensory assessment undertaken at admission, and that individual sensory needs should inform care. We also propose that inpatient mental healthcare facilities take sensory processing into consideration more thoroughly and train its clinicians accordingly, as the benefits are likely to extend beyond autism. In addition, both sensory-seeking and sensory-avoiding needs should be accommodated by designing purpose-built rooms within the ward.

Poster title Interpersonal Violence in Autism: Prevalence, Risk Factors, and Outcomes of **Victimisation** 

Author(s) Kassandrah Cooke<sup>1</sup>, Kathryn Ridgway<sup>1</sup>, Elizabeth Westrupp<sup>1</sup>, Darren Hed-

ley<sup>2</sup>, Merrilyn Hooley<sup>1</sup>, & Mark A. Stokes<sup>1</sup>

Author affiliation(s) <sup>1</sup> Healthy Autistic Life Lab, School of Psychology, Deakin University, VIC, Australia

<sup>2</sup> Olga Tennison Autism Research Centre, La Trobe University, VIC, Australia

Kassandrah Cooke - cookek@deakin.edu.au Presenting author Conflict(s) of interest N/A

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> In this study, we examined the prevalence, risk factors, and outcomes associated with interpersonal violence among autistic individuals. A total of 45 studies were included in this review. Age, gender, and autism severity were identified as key risk factors for various forms of victimisation. Victimisation was also associated with negative mental health outcomes and suicidality. The importance of these findings and the lack of research on this topic warrants further research on the nature of interpersonal violence in autism and appropriate interventions to improve the safety of autistic individuals.

**Background:** 

Current research demonstrates that autistic individuals experience heightened levels of risk for interpersonal violence. Hence, interpersonal violence is a matter of importance in Autism Spectrum Conditions (hereafter 'autism'). Research also indicates that when experiencing this violence, their outcomes are relatively worse than that of the general population. Within the framework of the multiple minority stress model, it is highly likely that gender minorities such as female and non-binary groups may experience even further increased risk.

## **Objectives:**

Our study undertook a comprehensive systematic review of published literature addressing interpersonal violence in autism.

## Methods:

We undertook a systematic database search identifying studies assessing exposure to interpersonal violence. We defined interpersonal violence as any act resulting in physical, sexual, or psychological violence between individuals. From the search, 45 studies of varying methodologies and designs were identified as meeting inclusion criteria.

# Results:

From the synthesis, we identified multiple risk factors for interpersonal violence associated with autistic individuals. Gender variance was associated with increased risk. Poorer mental health outcomes were apparent in the data, again, emphasized by membership of a gender minority, or female gender. Further, age was identified as a relevant factor, as was autism severity.

# **Conclusions:**

There are multiple areas of concern that would benefit from intervention. These include age, gender, and autism severity. We also found that violence exposure adversely impacted mental health and was associated with suicidality. The severity of outcomes, and the absence of relevant research reveals a need for additional research both into the nature of the problem and interventions to support those experiencing this.

**Abstract** 

Lay abstract

Poster title

Exploring autistic people's perspectives on their use of, and barriers to mental healthcare access and services in Australia

Author(s)

Kathleen Denney<sup>1</sup>, Mark A. Stokes, PhD<sup>2</sup>, Susan M. Hayward, PhD<sup>3</sup>, David Nicholas, PhD, RSW<sup>4</sup>, Angela Clapperton, PhD<sup>5</sup>, Cheryl Dissanayake, PhD<sup>1</sup>, Jo Robinson, PhD<sup>6,7</sup>, Julian Trollor, MD<sup>8</sup>, Mirko Uljarević, MD, PhD<sup>9</sup>, & Darren Hedley, PhD<sup>1</sup>

Author affiliation(s)

<sup>1</sup>Olga Tennison Autism Research Centre, School of Psychology & Public Health, La Trobe University, Melbourne, VIC, Australia

<sup>2</sup>School of Psychology, Deakin University, Melbourne, VIC, Australia

<sup>3</sup>School of Social and Political Sciences, University of Melbourne, Melbourne, VIC, Australia

<sup>4</sup>Faculty of Social Work, University of Calgary, Edmonton, Alberta, Canada

<sup>5</sup>Melbourne School of Population and Global Health, University of Melbourne, Melbourne, VIC, Australia

<sup>6</sup>Orygen, Melbourne, VIC, Australia

<sup>7</sup>The Centre for Youth Mental Health, University of Melbourne, Melbourne, VIC, Australia

<sup>8</sup>Department of Developmental Disability Neuropsychiatry, School of Psychiatry, UNSW Sydney, NSW, Australia

<sup>9</sup>School of Psychological Sciences, University of Melbourne, Melbourne, VIC, Australia

Presenting author Conflict(s) of interest

Kathleen Denney - k.denney@latrobe.edu.au

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**Funding** 

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Lay abstract

Suicidal thoughts and behaviour, are over-represented in autistic people when compared to the general population. However, autistic adults often have difficulty accessing appropriate mental health support in Australia. We interviewed 17 autistic adults, to learn about their experiences of seeking and receiving mental health support. Participants highlighted some key barriers to accessing mental health services and identified limitations to the mental health support provided. We will use the findings from this study to make recommendations for how mental health services in Australia can be improved for autistic adults.

#### **Abstract**

#### Background:

Suicidal ideation and behaviour, including deaths, are over-represented in autistic people when compared to the general population, with up to a ninefold increase in premature death by suicide being reported in the literature [1-2]. Despite this, autistic adults have difficulty accessing appropriate mental health supports in Australia [3]. There is currently insufficient research evaluating access to, and gaps in mental health service provision related to risk assessment and suicide prevention in autism.

#### **Objectives:**

To explore autistic adult's perspectives on their use of, and barriers to mental healthcare access and services in Australia.

#### Methods:

Seventeen autistic adults (59% women,  $M_{\rm AGE}$  = 43.71, SD = 11.66) with a history of at least one verified suicide attempt participated in this qualitative study. Based in phenomenology, semi-structured interviews were conducted, using an interview schedule that was developed collaboratively with autistic people. Data analysis was based on a thematic analysis approach.

#### Results

Participants identified barriers to service access. Key mental health support quality indicators and limitations of service provision in these areas were also discussed.

#### **Conclusions:**

The findings from this study highlight the need for improvements in both access to and provision of mental health services for autistic adults.

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Poster title A Qualitative Exploration of the Impact of Camouflaging Behavior on the Mental

Health and Wellbeing of Autistic People, Experienced During a Job Interview

**Author(s)** Mikaela Finn<sup>1</sup>, Rebecca Flower, PhD<sup>2</sup>, & Darren Hedley, PhD<sup>1</sup>

Author affiliation(s) 
<sup>1</sup>Olga Tennison Autism Research Centre, School of Psychology & Public Health,

La Trobe University, VIC, Australia

 $^{2}\mbox{Department}$  of Psychology and Counselling, School of School of Psychology &

Public Health, La Trobe University, VIC, Australia

Presenting author Mikaela Finn - Mikaela-finn@hotmail.com

Conflict(s) of interest No.

Darren Hedley is supported by a Suicide Prevention Australia National Suicide

Prevention Research fellowship.

Lay abstract Camouflaging has been shown to have a significant impact on autistic people'

Camouflaging has been shown to have a significant impact on autistic people's mental health and wellbeing. This study explored the mental health impacts of camouflaging behaviour in autistic people as experienced during job interviews. During job interviews, autistic participants reported engaging in camouflaging behaviour, which they noted required significant effort. This resulted in negative consequences including increased stress, anxiety, exhaustion, and led to burnout. Implementing changes to the job interview can improve autistic people's wellbeing by relieving pressure to hide their autistic traits. Based on these findings, specific suggestions for improving autistic people's mental health are provided.

Abstract Background:

Camouflaging has been shown to have a significant impact on autistic people's mental health and wellbeing [1-2]. Due to communication differences, autistic people may feel pressure during job interviews to hide their autistic traits by mimicking non-autistic people's behaviour to secure employment [3-4]. To date, limited research has investigated the impacts of camouflaging behaviour on autistic people's mental health, and current investigations have yielded conflicting findings [1-2]. This study provides insights into the toll that trying to "act normal" and "fit in" has on autistic people's mental health.

## Objectives:

To examine the mental health impacts of camouflaging behaviour in autistic people as experienced during job interviews.

## Methods:

This qualitative study included ten autistic adults (50% women, 20% men, 30% other, Mage = 34.10, SD = 8.90) with job interview experiences. Based in phenomenology, semi-structured interviews were conducted, using an interview guide developed in collaboration with autistic advisors. Thematic analysis was used to analyse the data, and interpretation was discussed with an autistic advisor.

## Results:

During job interviews, autistic participants reported engaging in camouflaging behaviour, which they noted required significant effort. This resulted in negative consequences including increased stress, anxiety, exhaustion, and led to burnout. These impacts were felt prior to, during, and after the job interview, with potential long-term effects on their wellbeing.

## **Conclusions:**

Implementing changes to the job interview can improve autistic people's wellbeing by relieving pressure to hide their autistic traits. Based on these findings, specific suggestions for improving autistic people's mental health are provided. Poster title Co-design of a Community-based Autism and LGBTIQA+ Inclusive Suicide

**Prevention Education Tool** 

**Author(s)** Karien Hill, PhD<sup>1</sup>, Carina Chan, PhD<sup>1</sup>, David Murphy<sup>2</sup>, Josie Barbaro, PhD<sup>2</sup>, &

Darren Hedley, PhD2

**Author affiliation(s)** <sup>1</sup>School of Psychology and Public Health, La Trobe University, VIC, Australia

<sup>2</sup>Olga Tennison Autism Research Centre, La Trobe University, VIC, Australia

Presenting author Dr Karien Hill - k3hill@ltu.edu.au

Conflict(s) of interest N/A

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Prevention Research Fellowship awarded to Darren Hedley. Research funding

was also received from Untapped Holdings.

Lay abstract Autistic and LGBTIQA+ individuals were consulted to review and change an

existing evidence-based community suicide prevention tool. The aim was to, through co-design, ensure the tool was inclusive to ensure the community are educated on how to detect and respond to suicide risk in others, including autistic and LGBTIQA+ individuals. The co-design significantly improved the current tool to become 'The Suicide Response Project'. The next steps are to examine the efficacy and usability of an online version of the tool in large, communi-

ty-based samples.

#### Abstract

## Background:

There is significant intersectionality of autism and LGBTIQA+ identities; however, this intersectionality is rarely addressed by researchers from either field. Given high suicide rates among autistic and LGBTIQA+ people, there is a need for suicide prevention tools that consider this intersectionality. Here, we describe the co-design with autistic and LGBTIQA+ people of a new community-based suicide prevention education resource, the Suicide Response Project (SRP). SRP draws from the Bystander Intervention Model (Darley & Latané, 1968) and aims to educate the community on detecting and responding to suicide risk. Our preliminary research with the SRP modules found them to be effective in increasing readiness, confidence, intent and skill to detect and respond to suicide risk (Hill, Somerset, Schwarzer, & Chan, 2020).

## **Objectives:**

To describe the co-design process and outcomes for a new evidence-based suicide prevention education tool.

## Methods:

Following guidelines for participatory research and co-design (Nicolaidis et al., 2019; Staniszewska et al., 2017), autistic and LGBTIQA+ people with lived experience of suicide ideation and behaviour were engaged in refining the SRP modules to include content that was specifically relevant to them.

#### Results

This process led to: 1) use of strength-based language; 2) emphasis on community advocacy and peer support; and 3) concerns related to stigma and stereotyping. This information was incorporated into the modules.

## **Conclusions:**

The co-design process with autistic/LGBTIQA+ people led to clear improvements to SRP modules. The next steps are to examine the efficacy and usability of the online version of SRP in large, community-based samples.

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Poster title Trait Anxiety in Individuals on the Autism Spectrum: A Systematic Review

Author(s)
Rebecca Jolliffe¹, Dawn Adams¹, & Kate Simpson¹
Author affiliation(s)
¹Autism Centre of Excellence, Griffith University

Presenting author
Rebecca Jolliffe - rebecca.jolliffe@griffithuni.edu.au

Conflict(s) of interest N/A

**Funding** Australian Research Council, Commonwealth Government's Research Training

Program, and Griffith University

Lay abstract Trait anxiety refers to general tendency towards anxiousness. Its measurement

may allow exploration of impairing anxiety symptoms that don't meet cut-offs for anxiety disorder diagnosis. This review gathered research that has been completed on trait anxiety in individuals on the autism spectrum, to investigate the characteristics, methods, quality, and findings of these studies. It was found that individuals on the autism spectrum score higher on standardised measures of trait anxiety. However, these measures were designed for neurotypical individuals, and research is still needed to check if they are also appropriate to

assess trait anxiety in individuals on the autism spectrum.

Abstract Background:

Anxiety is a highly prevalent co-occurring mental health condition in individuals on the autism spectrum, associated with poor long-term outcomes and decreased quality of life. Trait anxiety describes a relatively stable personality trait of anxiety proneness and increased threat perception. Although the state-trait model of anxiety is well described in neurotypical literature, its study in autism research is ill-defined.

**Objectives:** 

This systematic review aimed to summarise the characteristics, methods, outcomes, and quality of research that has investigated trait anxiety in individuals on the autism spectrum.

Methods:

Systematic electronic searches yielded 1099 records, and 23 studies met criteria for inclusion in the review.

Results:

Overall, study participants were mainly males from western countries, with no representation of older adults (>60 years) or individuals with intellectual disability. Trait anxiety was measured using self-report subjective questionnaire measures in all articles, with two including additional parent-report measures. Most studies gave no psychometric details of their chosen trait anxiety measure and 21 studies used standardised subjective measures that have not yet been validated for use in participants on the autism spectrum. Assessment using STROBE and CONSORT checklists indicated areas of strength and weakness in reporting. Eighteen studies compared individuals on the autism spectrum with control groups of participants without an autism diagnosis, and most reported significantly higher trait anxiety scores in participants on the autism spectrum.

Poster title Suicidal Ideation as A Grief Response Among Autistic Adults

**Author(s)** Jennifer Lowe<sup>1</sup>, Bruce Rumbold, PhD<sup>2</sup>, & Cheryl Dissanayake, PhD<sup>3</sup>

Author affiliation(s) <sup>1</sup>Department of Public Health

<sup>2</sup>Public Health Palliative Care Unit

<sup>3</sup>Olga Tennison Autism Research Centre, School of Psychology and Public

Health, La Trobe University, Melbourne, VIC, Australia

Presenting author Jennifer Lowe - j.lowe@latrobe.edu.au

Conflict(s) of interest N/A Funding N/A

**Lay abstract**This study is about autistic adults' experiences of grief and bereavement.
Suicidal ideation may be a response to grief that is experienced by autistic

Suicidal ideation may be a response to grief that is experienced by autistic adults when death is anticipated, it serves as an effective coping strategy and is used as a means of emotional expression and/or problem solving. Autistic adults bereaved by suicide perceived the suicide as a form of social rejection and an unnatural cause of death. Suicidal ideation as a response to grief may be minimised through strategies such as decreasing the number of unknown variables surrounding death, preparing for grief when possible and

actively increasing support networks.

Abstract Background:

Autistic adults' experiences of grief and bereavement have largely been overlooked by researchers, healthcare services and mental health practitioners. This qualitative study sought to explore autistic adults' experiences of being

bereaved and adjusting to grief.

Methods:

A total of 42 semi-structured in-depth interviews were conducted with bereaved autistic adults (n=20) and healthcare professionals (n=22) across palliative care, funeral and bereavement service contexts. The data were analysed using grounded theory.

Results:

Five themes relating to suicidal ideation emerged. Autistic adults described suicidal ideation as an automated response to anticipatory grief, an effective coping strategy, a solution when problem solving and a means of emotional expression. Autistic adults bereaved by suicide reported their grief response as notably 'different' to other losses, perceiving suicide as a form of social rejection and an 'unnatural' cause of death. Given the 'Public Health Model of Bereavement Support' identifies those bereaved by suicide at higher risk of developing prolonged grief disorder, autistic adults bereaved by suicide are more likely to require formal support from mental health or grief professionals.

Conclusion:

Bereaved autistic adults and healthcare professionals suggest suicidal ideation as a response to grief or bereavement can be minimised using simple strategies. These include decreasing the number of unknown variables surrounding death, preparing for grief and bereavement when possible and actively increasing the autistic adults' support network. Informal supports such as family members or friends are considered just as effective, and in some cases more effective, than formal supports such as qualified mental health practitioners.

Poster title Discordance between self-report and proxy-reported quality of life outcomes

Author(s) Melanie Martinelli

Author affiliation(s)

Abstract

Presenting author Melanie Martinelli - Melaniemartinelli@hotmail.com

Conflict(s) of interest N/A Funding N/A

**Lay abstract** Even though we have many evidence-based intervention and support strate-

gies for autistic people, by standardised measure autistic people have some of the poorest quality of life outcomes in the world. Due to differences in communication and sensory profiles, autistic people can have a very different subject experience compared to the non-autistic population. This poster focuses on the difference between what autistic people say about their quality of life vs what other people measure their quality of life. To see if intervention strategies were improving wellbeing quality of life outcomes across time was

also documented.

Quality of life is a subjective measure designed to measure an individual's wellbeing. Differences in autistic development can mean their subjective experience is different to non-autistic people. Autistic people experience some of the world's poorest quality of life outcomes. One theory is that there is a difference between proxy and self-report and how those outcomes are used to

develop supports.

**Background:** 

**Objectives:** Investigate the differences between proxy and self reported outcomes.

To see if there is a difference in gol over time.

To investigate differences in proxy and self reported outcomes

## Methods:

A literature review was conducted to find qol papers that used the Who-QOL Bref or the PedsQL to measure well-being in the autistic population between 2009 and 2020. Outcome data was divided between adult and child outcomes as well as proxy or self-report find differences between the groups. The data was also compared to see if there was an improvement in wellbeing overtime

## Results:

Trends in overestimating autistic wellbeing by proxy report were consistent in both child and adult assessment, across all domains except social wellbeing, where children self-reported their wellbeing as higher than their parents did. Quality of life remains consistent across time. There are inconsistencies between self/proxy and adult/child wellbeing indicators

## **Conclusions:**

Understanding the differences in proxy and self reported outcomes, using wellbeing as a measure of program success, and using adult self-reported data as a framework for program development may lead to better supports and interventions for autistic people.

Poster title Autistic wellbeing and how it can be supported - Can we really homogenise

a heterogeneous, non-homogeneous group and expect good wellbeing out-

comes?

Author(s) Melanie Martinelli

Author affiliation(s)

Presenting author Melanie Martinelli - Melaniemartinelli@hotmail.com

Conflict(s) of interest N/A
Funding N/A

Lay abstract

Whilst autistic people share a series of traits, due to the difference in the autistic neurological profile, co-occurring conditions, sensory experience and the environment they grew up in, each autistic person is so unique that one can

not be reliably measured against the other.

High-quality research relies on large randomised control trials, with generalised outcomes and literature reviews that further dilute the individual nature of autistic people. This poster investigates if generalising a subjective experience, like quality of life, is the right approach to improving wellbeing in such a

diverse population.

Abstract Background:

The autistic population is a heterogeneous, non homogeneous group of individuals, made up of core autistic features and multiple, varying co-occurring conditions. Should we be relying on proxy-reported studies, or large homoge-

nised studies to understand individual wellbeing?

Objectives:

What increases, decreases or has not impact on autistic wellbeing, How are outcomes measured to understand program success, and lastly, Develop a framework for support or intervention based on these results

Methods:

A literature review was conducted compile data on

What increases, decreases and has no effect on autistic quality of life Reporter type

If the paper was a general measure of QoI or if it was reporting on an intervention

These results were synthesized into a framework designed around the outcomes of autistic voices

Results:

There is discordance between what autistic people say improve their wellbeing and the support strategies used in intervention.

Improved wellbeing should be how program success should be measured yet programs rarely collect this data. Few programs provide an individualised approach, many rely on proxy reported data to draw conclusion to program success, self-reported data we do have on what improves wellbeing for autistic people is rarely the focus of intervention.

Individuals with a co-occurring intellectual disability or communication disorder are often left out of research, which leaves their experiences unaccounted for.

Conclusions:

An urgent and radical re-think of how wellbeing in the autistic population is measured and understood is required. Smaller studies, that allow for individualised outcomes should deliver more reliable data on how to support wellbeing.

Poster title Supporting Autistic Autism Researchers Through the Detrimental Impacts of

**Autism Research** 

Author(s) Gilly-Elle McKeown¹
Author affiliation(s) ¹University of Tasmania

Presenting author Gilly-Elle McKeown - Gillyelle.mckeown@utas.edu.au

**Lay abstract** Autistic people working in autism research are exposed to a dehumanising

narrative about themselves and the community with which they identify. As a result, they can feel stigmatised, isolated and undervalued, often leading to challenges with their mental health. Therefore, it is essential to understand what is occurring in the field by looking at the emerging literature in this area to make adjustments that will assist the mental well-being of autistic autism researchers.

Abstract Background:

Autistic people have a higher likelihood of mental health difficulties than non-autistic people. Stigmatised by the dehumanising and inaccurate narrative about autism can make autistic people feel isolated and traumatised. Autism research has long perpetuated this negative perception of autism, and working in the field as an autistic researcher can be detrimental to mental health. Autistic researchers are passionate and highly skilled people and offer their own lived experiences and insider insight into the priorities of the autistic community. However, due to the difficulties researchers such as Botha (2021) feel, many autistic people are concerned academia is not a safe space for them and thus leave the profession. Therefore, it is crucial to find out what is occurring in the field to infer what changes we can make to retain these

excellent researchers and protect their mental well-being.

Objectives:

The objective was to identify literature relating to particular difficulties autistic autism researchers face and investigate what is currently occurring for autistic autism researchers.

Methods:

The author conducted a literature review on the topic, utilising academic literature written by autistic autism researchers.

Results:

The two primary themes uncovered as part of this review are: (1) Deficit-Based Autism Narrative and (2) Structural Barriers.

**Conclusions:** 

Suggestions for adjustments are presented, which, if implemented, will assist the mental health of autistic autism researchers and ensure it is easier to retain their skills.

Poster title Exploring the relevance of the interpersonal theory of suicide in autistic

people

**Author(s)** Rachel Moseley<sup>1</sup>, Nicola Jean Gregory<sup>1</sup>, Paula Smith<sup>2</sup>, Carrie Allison<sup>2</sup>, Sarah

Cassidy<sup>3</sup>, & Simon Baron-Cohen<sup>2</sup>

Author affiliation(s) <sup>1</sup> Department of Psychology, Bournemouth University, Poole, UK

<sup>2</sup> Autism Research Centre, Department of Psychiatry, University of Cam-

bridge, UK

<sup>3</sup> School of Psychology, University of Nottingham, UK

Presenting author Rachel L. Moseley

rmoseley@bournemouth.ac.uk

Conflict(s) of interest

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for ECRs)

**Lay abstract** Theories explaining suicide are important for identifying individuals at risk and

highlighting potential avenues for intervention. Suicide ideation, suicide attempts and deaths are very common in the autistic community, but are poorly understood. The present study investigated whether one very popular theory, the interpersonal theory of suicide, was also relevant for autistic people. The findings suggest that the theory is relevant to a point, but that suicide in autistic people differs from suicide in non-autistic people. Feelings of being a burden to others seem especially toxic, and reduced fear of death also seems

connected to suicide attempts.

Abstract Background:

While there are known risk factors for suicidality in autism, these are often unconnected from theoretical frameworks that might explain *how* risk is ele-

vated and guide clinical interventions.

**Objectives:** 

The present study investigated the relevance of constructs from the Interpersonal Theory of Suicide (ITS), including perceived burdensomeness, thwarted belongingness and acquired capability for suicide, and explored mechanisms through which certain risk factors (relationship status, age at diagnosis, and

co-occurring ADHD) elevate suicide risk.

Methods:

Autistic adults (n = 314) completed an online survey, following which linear and multinomial regression was used to disentangle contributions of ITS variables from those of depression and anxiety for past-year suicide ideation,

past-year and lifetime suicide attempts.

Results:

Past-year suicide ideation was associated with burdensomeness, mental rehearsal of suicide plans (a facet of acquired capability), and depression. Burdensomeness and reduced fear of death differentiated those who had attempted suicide from those who had (and had not) experienced suicidal ideation in the past year. Mediation analyses revealed that relationship status and co-occurring ADHD were associated with past-year suicide ideation via burdensomeness, depression and anxiety. ADHD co-occurrence was also associated with lifetime suicide attempts via feelings of burdensomeness.

**Conclusions:** 

Burdensomeness and acquired capability appear potentially important to suicide in autistic people, but future research requires longitudinal designs to explore the temporal dynamics in suicide trajectories.

Poster title Stress and Wellbeing in Autistic Adults: Exploring the Moderating Role of

Coping

**Author(s)** Melanie Muniandy<sup>1,2</sup>, Amanda Richdale<sup>1,2</sup> & Lauren Lawson<sup>1,2</sup>

Author affiliation(s) 10lga Tennison Autism Research Centre, School of Psychology & Public

Health, La Trobe University, Victoria, Australia

<sup>2</sup> Cooperative Research Centre for Living with Autism (Autism CRC), Brisbane, Queensland, Australia

Presenting author Conflict(s) of interest

Melanie Muniandy - m.muniandy@latrobe.edu.au

N/A

**Funding** 

Autism CRC

Lay abstract

The stress literature suggests that high stress is related to low wellbeing. This research explored how coping strategies might influence (i.e., weaken or amplify) this relationship between stress and wellbeing in autistic adults. We found that higher use of engagement coping strategies appeared to weaken the relationship between stress and wellbeing, especially at high levels of stress. Supporting the development and use of engagement coping strategies in autistic adults may be useful in the promotion of wellbeing in this population.

**Abstract** 

## Background:

The wider stress literature suggests negative associations between stress and psychological wellbeing. Similarly, the use of adaptive (e.g., engagement coping) and maladaptive (e.g., disengagement coping) coping strategies have been related to improved and reduced wellbeing respectively. However, the extent to which coping strategies may also moderate the relationship between stress and wellbeing is less known.

## **Objectives:**

To examine the potential moderating (i.e., buffering or exacerbating) role of coping in the relationship between stress and wellbeing in autistic adults.

## Methods:

Sample consisted of 86 autistic adults, aged 19-74 years, recruited through an online study. Using two moderation models, we explored whether the relationship between stress (stress composite using PSS and DSI scores) and wellbeing (WEMWBS) was moderated by use of engagement coping and disengagement coping strategies (Brief COPE).

## Results:

Engagement coping had a significant effect on wellbeing directly (b: 0.57, p < 0.01) and indirectly, through an interaction with stress (b: 0.21, p = 0.02). Disengagement coping only had a significant direct effect on wellbeing (b: -0.76, p < 0.01), with its indirect effect not reaching statistical significance (b: -0.02, p = 0.86).

## **Conclusions:**

Our findings suggest differential mechanisms under which engagement and disengagement coping strategies operate in the stress-wellbeing relationship. Specifically, engagement coping has both a promotive (direct) and buffering (indirect) role, while disengagement coping has a risk (direct) role only. We highlight the importance of honing engagement coping strategies in autistic adults, where its potential stress-buffering role may be especially beneficial in the context of high stress.

Poster title Women seeking an autism diagnosis in Australia: What helps and what hin-

ders?

**Author(s)** Sarah Murphy<sup>1</sup>, Rebecca L Flower<sup>1</sup>, Rachel Jellett<sup>2</sup>

Author affiliation(s) <sup>1</sup>Department of Psychology and Counselling, School of Psychology and Public

Health, La Trobe University, Vic, Australia

<sup>2</sup>Olga Tennison Autism Research Centre, School of Psychology and Public

Health, La Trobe University, Vic Australia

Presenting author Sarah Murphy - <u>18968162@students.latrobe.edu.au</u>

Conflict(s) of interest N/A
Funding N/A

Lay abstract Accessing

Accessing an autism diagnosis, though important, can be difficult for autistic women. We explored what things made getting an autism diagnosis easier and harder by interviewing ten autistic women. It helped when women recognised their autism, saw value in being diagnosed, prepared for assessment, unmasked, and were persistent. Their experience depended on whether providers were accommodating and knowledgeable, and whether providers were dismissive. The diagnosis cost, time requirements, and criteria and tools also impacted women's experiences. Education for providers, and resources for women, are needed to make autism diagnosis more accessible for women.

Abstract Background:

There is currently limited research into the barriers and facilitators women encounter when seeking an autism diagnosis in Australia. Given an adulthood autism diagnosis can increase women's self-compassion and inform appropriate psychological support, it is important for women to have access to diagnostic services with as many facilitators and as few barriers as possible.

Objectives:

This study aimed to comprehensively explore what helped and hindered autistic women during the adulthood autism diagnostic process.

Methods:

Ten autistic women who were diagnosed after the age of 18 in the past five years participated in a semi-structured interview about what made their diagnostic process easier and harder.

Results:

Analysis revealed a model with barriers and facilitators on person-, provider-, and system-levels. System-level factors included requirements placed on those seeking diagnosis and the nature of assessment tools and criteria. That system provided the context in which person-level and provider-levels operated and interacted. Person-level barriers and facilitators related to the woman's motivation, preparation, support, and approach during assessment. Provider-level barriers and facilitators included providers' knowledge and skill in working appropriately with autistic women, and providers dismissing and misattributing autistic traits

**Conclusions:** 

The results of this study highlight areas for improvement so women can access autism diagnosis and the associated wellbeing benefits more easily. Training is needed to improve provider knowledge of the heterogeneity of autism, the role of gender in autism, and the significance of communication accommodations and personal validation. Advisory resources for autistic women and healthcare providers would also be helpful.

## Poster title

## Suicidal Behaviour in Australian and Canadian Children, Adolescents, and Adults on the Autism Spectrum

## Author(s)

Ensu Sahin<sup>1</sup>; Kat Denney<sup>1</sup>; Kailyn Turner<sup>2</sup>; HangselSanguino<sup>2</sup>; Simon M. Bury, PhD<sup>1</sup>; Mirko Uljarevic MD, PhD<sup>3</sup>; Angela Clapperton PhD<sup>4</sup>; Cheryl Dissanayake PhD<sup>1</sup>; Jo Robinson PhD<sup>5,6</sup>; Julian TrollorMD<sup>7</sup>; Mark A. Stokes, PhD<sup>8</sup>; Carly McMorris, PhD<sup>2†</sup>; &Darren Hedley, PhD<sup>1†</sup>

<sup>†</sup>Carly McMorris and Darren Hedley share senior authorship

## Author affiliation(s)

<sup>1</sup>Olga Tennison Autism Research Centre, School of Psychology and Public Health, La Trobe University, Melbourne, VIC, Australia

<sup>2</sup>Werklund School of Education, School of Applied Child Psychology, University of Calgary, Calgary, AB, Canada

<sup>3</sup>School of Psychological Sciences, University of Melbourne, Melbourne, VIC, Australia

<sup>4</sup>Melbourne School of Population and Global Health, University of Melbourne, Melbourne, VIC, Australia

<sup>5</sup>Orygen, Melbourne, VIC, Australia

<sup>6</sup>The Centre for Youth Mental Health, University of Melbourne, Melbourne, VIC, Australia

<sup>7</sup>Department of Developmental Disability Neuropsychiatry, School of Psychiatry, UNSW Sydney, NSW, Australia

8School of Psychology, Deakin University, Melbourne, VIC, Australia

# Presenting author Conflict(s) of interest

Ensu Sahin - ESahin@ltu.edu.au

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## Lay abstract

Autistic people show concerningly high rates of suicide. We aimed to characterise suicidal behaviour in autistic people including: age of first attempt; rate of non-suicidal self-injury vs suicidal attempts; lethality of suicide attempts. We found that over 60% of autistic people engaged in self-harming behaviour. The youngest age of first suicide attempt was 7 years, with adolescence shown to be a particularly vulnerable period for young autistic people. Our findings highlight the need for research to focus on developing and validating appropriate interventions, as well as improved methods for detecting young autistic people who may be experiencing suicidal thoughts.

## **Abstract**

## **Background:**

Autistic people show concerningly high rates of suicide. This study used the Columbia Suicide Severity Rating Scale (C SSRS) to characterise suicidal behaviour in autistic people including: age of first attempt; rate of non-suicidal self-injury vs suicidal attempts; lethality of suicide attempts in autistic people

## **Objectives:**

To examine the nature of suicidal behaviour in younger (Study 1: Canada) and older (Study 2: Australia) autistic people.

#### Methods:

In Study 1, caregivers (91% female,  $M_{AGE}$  = 41.25, SD = 6.7) of 33 young autistic people (male = 78.8%;  $M_{AGE}$  = 13.28, SD = 4.42 years), completed a caregiver-report version of the C-SSRS. In Study 2, 98 autistic adults (women = 58.2%, non-binary = 7.1%;  $M_{AGE}$  = 41.65, SD = 12.96 years) completed the C-SSRS interview version.

#### Results:

For Study 1, children with a history of suicide attempts reported from 1 to 4 attempts. For Study 2, autistic adults with a history of suicide attempts reported from 1 to 26 attempts across their lifespan. Age of first suicide attempt tended to be in mid adolescence.

## **Conclusions:**

Over 60% of both samples reported engaging in self-harming behaviour. The youngest age of first suicide attempt was 7 years, indicated across both samples. Adolescence is a particularly vulnerable period young autistic people. Given the young age at which autistic youth are attempting suicide, and high rates of self-harm, research needs to focus on developing and validating appropriate interventions, as well as improved methods for detecting young autistic people who may be experiencing suicidal thoughts.

Poster title Author(s)

The global burden of suicide among people on the autism spectrum

Damian F Santomauro<sup>1,2,3</sup>, Darren Hedley<sup>4</sup>, Ensu Sahin<sup>4</sup>, Alize J Ferrari<sup>1,2,3</sup>, & Mark A Stokes<sup>5</sup>

Author affiliation(s) <sup>1</sup>School of Public Health, The University of Queensland, Herston, Queensland,

4029, Australia

<sup>2</sup>Queensland Centre for Mental Health Research, Wacol, Queensland 4076,

Australia

<sup>3</sup>Institute for Health Metrics and Evaluation, University of Washington, Seattle,

Washington, USA

<sup>4</sup>Olga Tennison Autism Research Centre, School of Psychology and Public

Health, La Trobe University, Melbourne, Victoria, 3086, Australia

<sup>5</sup>Healthy Autistic Life Lab, School of Psychology, Deakin University, Geelong,

Victoria, 3220, Australia

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Damian Santomauro - d.santomauro@uq.edu.au

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Lay abstract

Our objective was to estimate the deaths and years of life lost due to suicide for autistic persons to inform policy makers and service planners. We analysed data sources reporting the risk of suicide for autistic persons and estimated that autistic persons were three times more likely to die by suicide than non-autistic persons. With this estimate, and estimates of suicide and autism spectrum prevalence, we estimated 12,500 suicides globally in 2019 were autistic persons. These findings will bring the burden of suicide experienced by autistic persons to the attention of policy makers with

the means to target this burden.

#### Abstract

## Background:

Health metrics, such as deaths and years of life lost (YLLs) have major influence and are widely used by policy makers and service planners globally. However, available health metrics do not capture the whole picture of service needs for autistic persons. Previous work suggests autistic persons are at elevated risk of mortality due to suicide, which is not reflected by the estimates currently available to service planners and policy makers.

## **Objectives:**

To estimate the number of deaths and YLLs of suicide for people on the autism spectrum.

## Methods:

We conducted a systematic literature review searching electronic databases for studies reporting the relative risk (RR) of death by suicide or suicide attempt for autistic persons. Estimates were pooled via meta-regression. Pooled RRs, and the prevalence of the autism spectrum and suicides from the Global Burden of Disease Study were then used to estimate the deaths by suicide and YLLs among autistic persons.

## Results:

The pooled RR for suicide for autistic persons was 3.2 (95% UI: 2.0-5.5). The estimated number of autistic suicides globally in 2019 was 12,500 (4,968-24,535), representing 1.6% (0.7%-3.2%) of all suicide deaths globally. This corresponded to 629,774 YLLs (269,760-1,221,462).

#### **Conclusions:**

Autistic persons are at a substantially higher risk of suicide compared to non-autistic persons and there is substantial loss of life and YLLs due to suicide among autistic persons. These findings will bring the fatal burden of suicide experienced by autistic persons to the attention of policy makers with the means to target this burden.

Poster title "I was done with the volcanoes in me":

Exploring the perspectives of young autistic people with lived experience of

suicidal ideation/behaviour and self-harm

Author(s) Linda Taimre<sup>1</sup>

Author affiliation(s) <sup>1</sup>University of Melbourne

Presenting author Linda Taimre - <a href="mailto:linda@lindataimre.com">linda@lindataimre.com</a>, <a href="mailto:linda@lindataimre

Conflict(s) of interest N/A

**Funding** Orygen Youth Health

Lay abstract Autistic young peop

Autistic young people have a high risk of suicidal behaviour and likely experience it differently to non-autistic people. However, no research has explored their experiences, so this is poorly understood. This project interviewed five young autistic people to understand how they experience suicidal behaviour. The interviews were analysed to describe three main themes. 1) Interpersonal and Intrapersonal Understanding Facilitates Connection to Self and Others; 2) Suicide and Self-Harm Arise from the Intolerability of Emotions, and 3) The Duality of Relating to Others. These findings suggest mental health services need to be flexible to meet the needs of autistic young people.

Abstract Background:

Autistic young people experience high rates of suicidal ideation/behaviour, with risk factors including being female and camouflaging autistic traits. Evidence suggests that current clinical practices and theories of suicidality may not adequately serve these young people due to differing needs and experi-

ences, however this has not yet been qualitatively explored.

**Objectives:** 

This project aimed to explore how autistic young people experience suicidal behaviour, the relationship between self-harm and suicide for autistic young people, their experience of seeking help from mental health services; and whether their experiences are influenced by their gender.

Methods:

Five young people (four female including one transfemale; one male) aged 15-25 (M = 17.6) with diagnoses of autism or self-identifying as autistic were recruited from the Orygen Youth Health Clinical Program and headspace centres in Melbourne, Australia. Data were collected from semi-structured interviews and analysed using reflexive thematic analysis.

Results:

Three main themes and three subordinate themes were described: 1) Interpersonal and Intrapersonal Understanding Facilitates Connection to the Self and Others; 2) Suicide and Self-Harm Arise from the Intolerability of Emotions (with subordinate themes: 2.1) Suicidal or self-harm actions tend to be quick and impulsive; 2.2) Suicide and self-harm can cause meta-distress); and 3) The Duality of Relating to Others (with subordinate theme 3.1) Connection within the therapeutic relationship tends to be slow and complex).

Conclusions:

These findings have implications for clinical practice that broadly relate to mental health services understanding, and flexibly adapting to, the needs of autistic young people.

## INTERVIEW TRANSCRIPTS

**Brenna:** I am Brenna Maddox. I am an assistant professor at the University of North Carolina at Chapel Hill. I am the implementation scientist for the University of North Carolina TEACCH Autism program.

Interviewer: Okay. What does the TEACCH Autism program entail?

**Brenna:** It is a program at the University of North Carolina at Chapel Hill. We have seven outpatient clinics across the state of North Carolina. So TEACCH really focuses on clinical services, research and training. So, a three part mission.

Interviewer: How does that background inform your perspective on some of the issues that are being discussed at this conference in terms of wellbeing, suicidality, what sort of things have you learned?

**Brenna:** That's a great question. So, my background is in clinical psychology. So, I have a background in assessing cooccurring psychiatric conditions in people on the spectrum along with assessing suicide risk in people on the spectrum. So, it was really through a lot of my clinical interactions that I first learned about how many people on the spectrum do experience suicidal thoughts and behaviours and then...

Interviewer: Did that shock you?

**Brenna:** At TEACCH, at the TEACCH Autism program, we are really focused on how we can disseminate evidence based practices into people's home communities. That has also informed my work quite a bit because I want to be able to get helpful practices to people where they can access them. Recognising that not everyone will be able to access treatment or access supports in a university based setting or an academic medical centre. We are really working on getting those evidence based supports out to all communities.

Interviewer: When you say all communities, I assume you mean the people around the autistic person as well. Why do you think that it's so important to get this information out there?

Brenna: I think it's very important to get information about suicide risk and suicide management out there because first of all many people are not even aware that individuals on the spectrum are at an increased risk for suicide. I know at least here in the United States, many clinicians, this was not part of their clinical training. So, it's not really on their radar when they are working with an individual on the spectrum.

Interviewer: What was different about you that it got on your radar? Why are you different?

Brenna: I think from my direct experiences, I think working directly with individuals on the spectrum and hearing them talk about their stories, hearing them talk about their lived experience both from my clinical work and also from my research. So, when I was a postdoctoral fellow at the University of Pennsylvania I led an interview study where I was interviewing autistic adults about their experiences with mental health services. Even though I was not directly asking about their experiences with suicidality, that came up quite a bit. Many people shared how they had really struggled with suicidal thoughts and behaviours. So just listening to those stories and recognising what an unmet need it is out there inspired me to want to research that more.

Interviewer: Can you tell me, just before I go onto the topic of your paper, what – tell me about this – do you perceive a gap in the goals between the autism advocacy groups and researchers who are doing the – those hard yards of actually finding out? Do you see a way – do you see any gap in the goals there and how do we bring that together if you do?

**Brenna:** I really like that question. So, yes, I think oftentimes there is a gap between what the autistic community, what self-advocates would like to see in research, what their priorities are for research and what researchers are actually focusing on. I think I have been guilty of that in the past as well. What I'm really excited about currently is my community partnered research where it's the priorities from the autistic community that really inform the study. So, working side by side with self-advocates not only once we get the funding and we're doing the study but even earlier when we're writing the grant proposal and coming up with the research questions, choosing the measures, things like that.

So, I think that it is possible to have research be more aligned with autistic priorities but it takes that collaboration. It takes listening. It takes really being open to learning more and in possibly changing what you thought maybe you wanted to research as the researcher. When you get that extremely valuable feedback that it's not a priority, it's not going to be perceived as helpful in the community. I think that's very important.

Interviewer: While I wouldn't say every researcher and person with autism lacks those soft skills - to get people to see your point of view and to persuade them to work with you - do you think it's challenging sometimes when you have, I suppose, those personality types or does it just take all sorts of different people?

**Brenna:** I think, yeah, I think having true autistic – that meaningful autistic involvement in a study, not just as the token advisor or consultant on a study but truly involving autistic people as collaborators, as co-researchers, it very much strengthens the overall process in the final product. It does take – it takes more time. I've learned that this past year, it takes more time. It takes more meetings and I think a lot more thoughtful communication but in the end, the end result is very worthwhile.

Interviewer: What sort of themes do you want to tease out at this conference from your own work?

Brenna: So, at the conference I'm really looking forward to fetching on a few key areas from research related to suicide risk in autism. So, I'm looking forward to discussing what we know about risk factors of suicide in people on the spectrum. One of my wonderful collaborators, Lisa Morgan is also presenting at the conference. She and I have been working with other team members as well to really think about what are the warning signs of suicide in people on the spectrum, those imminent or more immediate warning signs that a suicidal event may be imminent. So, I'm talking some about that as well. Then I always like to spend some time in a presentation on this topic talking about the supports, what's out there, what can we be doing to help individuals who may be experiencing suicidal thoughts and behaviours.

Interviewer: Do you think that autism researchers need to be necessarily polymaths in terms of getting across what services are available, understanding the personalities, looking at priorities from the point of view of the people affected and negotiating all these different stakeholders? It's a bumpy road, isn't it?

**Brenna:** I think it depends on the person, their role and their priorities. I'm a big believer in team science, that no one researcher is going to be able to figure out these big problems alone. So, it's collaborating with autistic individuals, other stakeholders as well, like you just mentioned.

So especially when we're thinking about suicide prevention practices. We need to be partnering with clinicians who are on the frontline, who are really dealing with these concerns every day in their clinical practice to find out what's going to work, what's going to work in practice, not only in a research lab or a university setting that has much more resources but in a community based clinic. Where they may be very burdened and not have a lot of resources to support their clients. So, I think that type of team science where you're reaching out to people from multiple disciplines and backgrounds is very important.

Interviewer: When you discovered autistic traits in yourself, was it a self-diagnosis?

**Lisa:** No, I was diagnosed by a psychologist when I was 48 years sold, 10 years ago.

Interviewer: So, I also received a late diagnosis for highfunctioning autism. When I received this diagnosis, I found myself look at past events through a different lens. How much has it changed your emotional landscape to have this diagnosis so late in life?

**Lisa:** Well, there's several different ways. One was relief, because I've been a teacher for 25 years, and I was fired from a

teaching position, or not invited back, and the sole reason was because I didn't fit in with the staff. I mean, I had parents come and ask the principal to hire me on again. The students - there was no problem that way. It was just I didn't fit in with the staff, and to be honest with you, I did not fit in with the staff. They just did - it actually reminded me of being in middle school, and middle school was not that fun for me.

So, it was a relief in finding out there's a reason why I don't fit in, but there was also a measure of sadness of all the years I missed out not - just wondering why I didn't fit in, wondering what was wrong with me. If I had known what it was, I think I would have just done those years differently.

Interviewer: You were a teacher in a secondary school?

Lisa: I taught all grade levels and all subjects pretty much. I didn't teach social studies.

Interviewer: You went back into academia after you finished this job, is that right?

**Lisa:** I did. After I got fired you mean? Yes, I went back and I worked at a private school that was - had mostly autistic kids for our student body and loved it there. I loved working with the autistic kids and I felt like I fit in for the first time ever.

Interviewer: In terms of your research work, how did that come about?

Lisa: Well, everything that I've done in the past six years started on 24 June 2015 when I found my husband died by suicide. Everything changed for me, like completely. I stopped teaching. I did try to go back, but I just couldn't be in the classroom any more. My nerves were pretty much shot, and I'd also gone through so much difficulty in trying to - just, the aftermath of suicide for a person. You have to work with their estate. You have to - there are so many things you have to do. I had to sell my home. I had to make sure my home was sellable, so I had to fix it up. You know, I had deal with his car, and I had to deal with just so many things, and all of it's in the social communication realm, and I had trouble with everything.

Then I lost my friendships, which I had worked very hard to develop, and I don't make friendships easily. So, the new people coming into my life felt just as hard as the old people leaving, or my friends leaving, because they didn't know what to do or say.

So, I was very much alone and struggling and had no skills, and neither did anyone else know how to help me. So, I wrote a book, and that was my first book, and then from there I started to have a conversation with the American Association of Suicidology. From there I started a committee, for the first time, on autism and suicide. I started speaking at conferences, and I wrote another book: PTSD in Autistic Adults. I developed the first autistic resources in the United States at the national level, and they were sent out to crisis centre workers so they would know how to help autistic people who call in.

Crisis centres - and text in for help. I ended up doing some research, and I've been part of research

projects. So, from teaching, my life just took a 180 degree turn, and now I'm full-time working in crisis support for autistic people.

Interviewer: What do you find that autistic people present with? You gave a little bit of detail there about your own experience, but what is it that they present with, in respect of issues around suicidal ideation, that's distinct from the general population. What sort of issues do they seem to come up against?

**Lisa:** Well, what's different for autistic people is they perseverate and they ruminate. So, if you get an idea in your head about possibly dying by suicide, it's hard to get that out of your head, because of the perseveration. Perseveration can just be an endless loop. It can be a back task. For a lot of times I had suicidal ideation, and it can just be a background task. I can be doing other things, but it's always back there twirling and ruminating and seems to never go away. So, there's that.

Then, social skills are needed to ask for help: who to ask for help, how to ask for help, what to say? Then, there's the masking. So, masking and camouflage can come into play. So, an autistic person can be in crisis and look completely calm. So, they're not helped, because people will look at them like a neurotypical person and go by their outward appearance, and they look fine.

Then, there's also a piece where, a lot of autistic people when they get into a crisis and they have suicidal ideation and it's getting worse for them and something else may have happened, they can lose their words, and not be able to even communicate. They might be able to write, but it's very difficult sometimes in a crisis to be able to communicate it all.

Interviewer: So, when a neurotypical person is looking on, what is it that they're looking for they won't find there?

Lisa: They're looking for crying. They're looking for, you know, just looking distraught. They're looking for communication, whether it's explaining something that just happened to them, or, I can't take it anymore. An autistic person may not - they may, but they may not also be able to say those things, or know they can say those things, because it's all wrapped up in social communication. They may be afraid to say those things because they don't know how it's going to be taken by the neurotypical person helping them.

Interviewer: Well, arguably any communication is social in nature because it takes two to tango there. So, is the issue that the autistic person is in a world where the odds are sort of stacked against them in terms of comprehension?

**Lisa:** In terms of what?

Interviewer: In terms of comprehension - that it's just wired differently.

**Lisa:** Yes, but there's also another - on the other side of all of what I just said about social communication, there's also an aspect of people thinking autistic people are suicidal when they're not. That would come about using the warning signs of suicide for the general population - some of them are just aspects of autism. So, for instance, if an autistic person were in a crisis, but may not be suicidal, and they go through the process, which includes asking about suicide.

The questions may be, you know, do you withdraw? Yes. But an autistic person may not say, but I do it for regulating myself, and I do it for self-care. They might just say, yes - they're answering the question.

Another question that's typically asked is, are you anxious? Do you have sleep issues? If they're seeing them acting, maybe in a meltdown, they may take it as a rage and just mark off that they're in a rage. As these warning signs for the general public are asked, and the answers are, yes, it's just very mistaken, because there are aspects of autism not - it's not necessarily warning signs of

suicide. Again, that social piece, the autistic person especially, if they are in some kind of crisis, may not be able to elaborate on why they do what they do.

Interviewer: What will you be contributing in terms of the paper, or the reading you'll be giving at the conference?

Lisa: I'm going to share a little bit of my journey, from - probably from the suicide of my husband to the journey through the difficulty of suicide to hope and healing, and now there's resources out there, and now there's more people paying attention to suicide, and people are more aware that autistic people's suicide rate is pretty high. It's a leading cause of premature death for autistic people, and a lot of people don't even understand that autistic people can be suicidal. So, there's a lot - I'm going to kind of go through my story in what's happened in the last six years for me.

Interviewer: Thank you very much.

Interviewer: Tell me your various particulars. What is your name and what is your title and where do you work?

**Phil:** I'm Phil Batterham, and I'm a professor at the Australian National University.

Interviewer: What do you teach? Oh, you can't hear me at all. What do

you teach?

**Phil:** So, I conduct research in mental health and in suicide

prevention.

Interviewer: Right. What drew you into that line of work, Phil?

Phil: Sorry?

Interviewer: Hmm. What was it about that line of work that caught your attention?

**Phil:** I've always been interested in human behaviour and in mental illness and trying to understand that. So, I've always been attracted to that area of research. It's a challenge, and it's interesting. There's a lot to discover still. So, I think it's a very rich and important area to conduct research and it's also underappreciated I think, how important it is.

Interviewer: What would be the sort of - I mean, if you were to try and describe a point of difference between suicide prevention and the general population, and then with autistic people, as compared with autistic people, what would you say about that difference? Where does that difference lie?

**Phil:** I think what we learn from suicide prevention research in general, a lot of it can be translated to working with people with autism spectrum. In my research I focus a lot on social aspects related to suicide risk. We find that things like feeling like you belong to the community and or feeling that you're not a burden on other people are positively associated with feelings of suicidal thoughts. So, it's important both in the general population and in people - specific populations such as people with autism spectrum that they're made to feel like they're part of a community and that they're valuable and belong.

Interviewer: Do you know, when I listen to you talk about these issues I'm reminded of Durkheim's work on suicide, which was obviously a very long time ago and not exactly up to date, but he describes a very important concept called anomie, which you are familiar with, yeah. How much - how important is it to take an interdisciplinary approach to this problem? It seems to sort of sit in a lot of different areas, doesn't it?

**Phil:** Yeah, I think modern suicide prevention research does draw on a lot of different disciplines from sociology, psychology, from Durkheim and beyond, but also from public health and learning how they can modify risk in a general population using public health approaches. I think we've learned a lot from each other, from using a lot of different interdisciplinary perspectives. Suicide prevention isn't a simple thing. There's not one thing that drives suicide in the population. There is a whole constellation of different risk factors. So, understanding the social, the psychological, the biological, the contextual factors that lead somebody towards suicidal thoughts and behaviours is really important.

Interviewer: What will you be presenting at the conference? I know a lot of academics write something within the couple of days prior. What are your thoughts on what you're going to present?

**Phil:** So, I'll be talking a bit about my research trying to understand some of the models of suicide, suicidal behaviour, understanding how social factors and psychological factors such as feeling like you belong and feeling like you're not a burden on other people, how that can impact on suicidal behaviour. I'll also be talking about some of my work around stigma. So, we know

that stigma of mental illness can have a major effect on people not seeking help and going to a professional. Similarly with suicide prevention, if people feel that there's a shame around talking about suicide they're less likely to disclose that and less likely to reach out and seek help.

Interviewer: Do you know, I'm really interested that you used the word belong several times. I mean, I just wonder, that is so important isn't it? You know, this is more of a personal question, but perhaps it'll have a revealing answer. So, I mean as someone with autism I'm aware that I don't belong in certain situations, particularly where I've had a less than sympathetic response to atypical behaviour. I mean, what would you - how much importance would you place on a sense of belonging when so much of the time that sense of belonging just isn't available?

**Phil:** Yeah, I mean this is exactly why suicide prevention requires a whole of community approach. So, it's not just enough to have the health services in place. If people feel like they don't belong in society then it's really hard to support somebody who's struggling with thoughts about suicide. So, a whole of community approach to building that awareness around both suicide prevention but also around neurodiversity I think is important in making sure that people feel like they do belong and do have an important role in society.

Interviewer: Yeah. You mentioned three particular areas, the social, the biological, and - gosh, I've now forgotten the third one.

Phil: Psychological.

Interviewer: Yeah. I mean, how would you weight those in terms of their importance to suicide prevention in autistic people? Is there really any answer to that?

**Phil:** I mean, the challenge with suicide prevention is that there are different factors that impact on suicide differently for different people. So, for some people it is a mental illness. For other people it can be a short-term trigger such as the job loss or a relationship breakdown that can lead to suicidal behaviours. For other people there are a range of other contextual factors that impact on their progression into suicidal thinking and suicidal behaviour. So, that's what sort of makes it such a challenging area to work in and to understand that it's not a simple weighing up of factors.

Overall, there are some factors in a population that are more important than others. Some of the suicide theory tries to get at what underlies those factors. So, mental health obviously is an important one. Then social connectiveness is also very important, but beyond that there is a range of other factors, substance use, short term triggers such as job loss or a relationship breakdown that can have a major impact on suicide.

Interviewer: So, this conference brings together researchers and advocates which are operating to a very different set of incentives. So, do you work much with advocacy groups? What would you say that the value of your work has to offer them?

**Phil:** So, a lot of my research involves hearing the voices of people with lived experience, both consumers, people who have had personal lived experience and dealt with the mental health system and carers, people who have a loved one with a mental health problem or with suicidal behaviours. That brings a lot of richness to research I think, and it's really important that those voices are heard, that it's not just the experts who are feeding into discussions around what is important. Understanding what is important to the people who are experiencing these conditions is really important and brings a richness and a deeper level of understanding to our research.

Interviewer: What would you say - and this will be my last question because you've given really substantive answers and I can definitely put something together, but I just wanted to ask you one final question. What would you say to people who are - they work adjacent to this issue, or they might be dealing with autistic people as part of their clinical practice or whatever it might be, or even their day to day lives and they listen to what you say and they say, oh, it's too complicated, I can't get my head around this? I can't be of help. What would you say to those people?

**Phil:** Well, we know that even brief and low intensity interventions or educational programmes can have a positive impact on attitudes, knowledge, and behaviour. So, it's not too late to - even some level of understanding, some level of knowledge around how to support a person who's going through a suicidal crisis can make a positive difference. So, don't sell yourself short. There are ways to better understand the process. Yeah, that's - sorry.

Interviewer: Yeah, no that's good. Don't sell yourself short is a good message, yeah. I'm just going to stop it.

Interviewer: All right, okay. We are good to go. So Sarah, if you could include the questions in your answers, like for example if you could give me your name, you would say my name is, or I am, that would be great. Because I'll going cut it together. Yeah, if you could give me your name and your position, your institution?

**Sarah:** My name's Sarah Cassidy, and I'm an Assistant Professor in the School of Psychology at the University of Nottingham in the UK.

Interviewer: What's your special subject – you were telling me a little bit about it; can you tell me something more about your specialism?

Sarah: Well for my PhD I actually focused on eye-tracking and kind of emotion recognition. I did a post-doc at the University of Cambridge at the Autism Research Centre, and I was asked to analyse some data from a specialist diagnostic

clinic, specialising in late diagnosis of Asperger Syndrome in adults in the UK. Across a nine-year period we asked every person who came through, who got a diagnosis of Asperger Syndrome, had they ever contemplated suicide and had they ever planned or attempted suicide.

We found incredibly high rates – really, really worrying rates of suicidal thoughts; 66 per cent of those late-diagnosed adults with Asperger Syndrome said that they had felt suicidal at some point in their life. My systematic review that I did as part of that research, I found no studies – no studies at all that had looked at this and I was absolutely shocked. So I completely changed my research course from looking at eye-tracking and emotion recognition to going into the field of understanding and preventing suicide. So now all of my research focuses on understanding and preventing suicide in partnership with autistic people.

Because when I started and there was absolutely another available, the first thing I thought that we should do was to do ask autistic people what the next steps should be and what they wanted to see happen, and what they needed.

Interviewer: What was their answer?

**Sarah:** Their answer was that they needed a lot of things. The first step...

Interviewer: Actually, sorry, I'm going to probably – I'm probably going to use this as a clip, so if you could say when I asked autistic people what they wanted, de-de-dah.

Sarah: Oh, I have to think.

Interviewer: Yeah, take your time.

**Sarah:** When I asked autistic people what they wanted to see change the most, their absolute top priority, they said that they wanted barriers to accessing support and treatments understood and removed.

Interviewer: What kind of barriers?

**Sarah:** Quite a few different barriers. So one of our research projects showed that a main barrier was that many autistic people were excluded from mental health services owing to the fact that they were autistic. But that a lot of clinicians were saying things such as well, we're not trained, we don't understand how to support autistic people, and therefore we don't have the expertise to help them, and that still happens now.

Interviewer: Mm-hm. The mental health practitioners that you would hope would be able to engage with autistic people, what kind of people do they currently help?

**Sarah:** In the UK, I think that all of our services are really, really stretched due to a long kind of era of austerity and lack of funding. So long waiting lists and lack of funding affects everybody, but it also particularly affects autistic people and that's what came out of our research as well that there's a really, really lack of funding, lack of knowledge, lack of expertise, lack of tailored flexible support that autistic people need.

Interviewer: To what do you attribute this particular absence of support for autistic people when you compare it to other mental health needs, for example?

**Sarah:** I think this lack of support and funding for autistic people to access mental health services and other support services, it stems from a lack of knowledge, a lack of research. So the top autism community priority that was identified as a James Lind priority setting exercise in the UK, identified understanding mental health problems in autistic people and interventions to address those as the absolute top priority. The truth is that we don't have those specialised interventions, those treatments to effectively understand in treatment to health problems in autistic people.

But we know from previous research, that using assessments, treatment strategies, interventions off-the-shelf developed for non-autistic people don't work for autistic people. So there's a real gap in understanding...

Interviewer: I see, right.

Sarah: ...and that needs to be addressed.

Interviewer: Yeah, so because you're designing services for people who developed differently in terms of how they understood the world as children, because it's a neurodevelopmental condition, is that the reason why, do you think?

**Sarah:** I don't quite understand the question.

Interviewer: Well for example, it's not a psychosis, it's a neurodevelopmental issue. So it's – like for example, like I mean I can only speak as someone who is autistic and had a late diagnosis; looking back on it I can kind of see that a lot of the interventions people made were on the basis of a version of reality that I didn't share. Do you think that has anything to do with it? I'm just spitballing now.

**Sarah:** It's possible – there's quite a few things that could be involved. I mean one is that perhaps mental health kind of specialised clinicians aren't taught a lot about neurodevelopmental conditions, like autism and other conditions. Because, like you say it's not a disease, it's not a mental health problem; it's neurodevelopmental condition. So perhaps it just hasn't been covered, and there has been a real disconnect.

This is what I found when I switched kind of fields, from looking at kind of theory of minds, emotion recognition where there's loads of research, to going into mental health and suicidality in autism research where there was nothing. I found a real disconnect between mental health research, suicidality research and autism research – just a really, really big chasm where nobody – there isn't any [cross-fertilisation] or kind of collaboration between those two fields.

So a lot of my work to try and address this and other priorities, is to try and bridge that gap and to try and create international forums and collaboration, so that researchers from different fields actually talk to each other and learn from each other, and don't reinvent the wheel. That's why I'm so excited to see this conference, because it's the first kind of one that I've seen that really, really specialises in bringing people together who are both interested in helping autistic people and also suicidality.

So I'm really excited to see that, because just four years ago, I didn't see many people, or any people apart from myself, interested in this area. So it's really great to see.

Interviewer: That's brilliant – you really sold it there actually, I've definitely going to use that there [laughs]. What else do I want to ask you? So it's a sort of interdisciplinary effort, I guess, I mean I remember reading Durkheim's work – about Durkheim's work on analysing suicide, I think he wrote a book called Le Suicide in I think it was like 1899 or something like that, and he describes the context of anomie in society, this feeling of normlessness. Honestly, I felt pretty – yeah, that really spoke to my experience of society, that it was not for me actually.

All of this, it's not for you – you know you need to get onboard with us. This is the sort of prevailing impression. That's a sociology text and I wasn't expecting to come across something that was – I suppose that spoke so clearly to a psychological distress, but that's what he was identifying. I don't know, does that spark any thoughts?

**Sarah:** Not fitting into society or feeling excluded from society is something that I'm also really interested in understanding. I think it's really, really relevant, like you were saying to the experience of autistic people. It also exists in suicide theory developed for non-autistic people as well. So in Joiner's, Thomas Joiner's model of the interpersonal psychological theory, he talks about thwarted belongingness. So it's not feeling accepted, it's not feeling like you're connected to others.

When we consulted with autistic people about their experiences, autistic people who felt suicidal, they described this experience as well. We have a number of papers now, a number of projects in partnership with autistic people who have explored this issue and found that autistic people are much more likely to, unfortunately, feel thwarted belongingness, this disconnection. That's associated with increased risk of feeling suicidal.

Interviewer: The one thing I've asked everyone that I've interviewed is, what – you know if you're talking about suicidality, how would you draw a distinction between – I suppose what is it that's particular to autistic people in terms of suicidality as an issue which will be distinct from suicidality as an issue for society overall?

**Sarah:** Unique kind of risk markers specifically for autistic people, like why do – why are autistic people more likely to feel suicidal. I think that that is the million dollar question; we're still trying to understand why that is the case. A lot of my work is looking for unique and shared risk markers, because autistic people have increased risk of experiencing a lot of the common risk markers that we know increased risk of suicide in the general population. Such as increased vulnerability, trauma, mental health problems, social isolation, not feeling that you fit into society, other co-occurring conditions.

We know all of these risk factors for suicide in the general population, and they occur at higher rates, unfortunately, for autistic people. But there might also be unique risk markers, and some of my research has tried to pull that out, to expand suicide models developed for the general population so they work better for autistic people. One of those things that I identified in partnership with a steering group of autistic people is something called camouflaging. So it goes back to...

Sorry?

Interviewer: Is that like masking?

**Sarah:** Yes. Yes it is. So camouflaging, or masking, is feeling like you have to camouflage or mask your autistic traits and characteristics in order to fit in better with others. My autistic steering group that I worked with said that was the single biggest risk factor and trigger for them in feeling suicidal. I found in two subsequent studies that this experience of camouflaging and masking who you are to try and fit in, increases feelings of thwarted belongingness. It's one of the most important predictors of suicidal thoughts in autistic people, after controlling for a lot of other things, like age, mental health conditions, living situation, and a lot of other risk factors.

Interviewer: Masking has a lot to answer for – I didn't realise this. Do you think there is a cultural problem in society where we expect people to mask in this way? I mean we can settle for services, but if the society always expects that the autistic person will toe the line – oh, do you have to get the door?

**Sarah:** Thanks – I just had to let somebody in.

Interviewer: That's all right. So this will be my last question and I'll let you go and have coffee. Yeah, so I'm sorry, I've forgotten what my question was – do you remember?

Sarah: I think it was something along the lines of...

Interviewer: Oh yeah...

Sarah: ...is it society's issue?

Interviewer: So you can provide all the services, but if the society expects the autistic person to mask, and I mean they're not licking it off a stone, they're doing it for a particular reason. So how do you deal with that?

**Sarah:** I think suicide prevention won't fall on any one particular service or any one particular thing. Suicide prevention has to be holistic; so it has to involve society, has to involve services, it has to involve people that are involved with the person – like anybody that they can meet – it has to be a holistic kind of view. If we fix services and fix those barriers, it won't fix everything; we still need to fix barriers to employment, barriers to accessing social spaces. It's definitely a societal issue – it's not just a service issue.

So I strongly believe that suicide prevention, particularly – well for everybody – but particularly for autistic people, will involve a change in societal attitudes, reducing things like stigma, increasing acceptance.

Interviewer: Beautiful. Well you've given me so much...

**Steve RG:** I'm Steve Ryan-Gledhill. In a number of bands. One of the most recent ones is The Charlemagne Project which is a seventrack country flavoured EP that was released as we were going into lockdown, available on Spotify, iTunes and most of the streaming networks.

**Interviewer:** Were you inspired by Charlemagne's attempt to unite Europe in the year 800, is that [what]...

**Steve RG:** No I wasn't. I was looking for an interesting name and Charlemagne I quite liked and most the people who I mentioned to couldn't spell it, let alone know who he was. So I thought that sounds pretty good to me. Anyway so the first song that I played in that

performance is called Now I Feel the Rain and it was written with a couple of friends of mine after the black Saturday bushfires.

Interviewer: The theme of the song is about recovery.

**Steve RG**: Yes, it is. It talks in the opening about what one might experience being in the path of an impending bushfire which unfortunately many people were around that time. Also were again when most of the Eastern Seaboard was alight a couple of years ago. So it opens with that but ends with the town banding together once the crisis has passed, and one thing you want with bad bushfires is a heavy drenching rain. Shifting Sand, I guess it's about accommodating changing situations, in this case personal rather than climatic or anything else and how you can't really take a direction because you're still trying to accommodate for the movement in everything. Shifting Sand being a metaphor for the instability that comes from a broken relationship for example.

Interviewer: Red Sash, tell me about Red Sash.

**Steve RG:** Okay so Red Sash is - I guess it's a story of a person who finds comfort, physical comfort and emotional comfort in the arms of another. The other turns out to be a street [worker] and he believes he can build something from that, but ultimately realises that the particular personality of that person is not going to change. He reluctantly has to let her go and carry on, is really what it's about. So it's really unrequited love I suppose.

**Interviewer**: Tell me about - I mean, I'm just, I suppose - I was impressed when you were talking by the fact that you had managed this sense of difference while also achieving a degree of success in your life and relationships, career, travel...

**Steve RG**: Okay I'll carry on the theme then. So I was very good academically, when I chose to be. Then I got into music. I would learn to play the guitar, played in bands and so on. Built a career in finance which at its peak I was Head of Asia. So I was travelling to all of the Asian countries plus trips to New York and London and Europe. But found that I could very easily spot the codified behaviour in each of the different cultures with whom I was dealing.

Interviewer: Tell me about the diagnosis and the effect on you.

**Steve RG**: Okay. So I was having some difficulty and started going to counselling. I was accused during and post these counselling sessions that I wasn't trying hard enough, wasn't opening up to my feelings. But subsequently found out that that was because they were assuming I was neurotypical. Whilst it can't be 100 per cent definitively prescribed because you can't go back to my early childhood and talk to people that knew me then, pretty firm diagnosis that I was high functioning Asperger's.

Once I found that out and started looking at what sort of things Asperger's feel and exhibit, a lot of my earlier life and my current life going forward made a lot of sense to me and gave me quite a deal of comfort in knowing that I was trying hard but I had to try in a different way. Much as I had been doing accidentally I guess through 20 or 30 years in order to thrive and survive, it gave me a context in which I did that. One of the counsellors I had who by then was an Asperger's Autism

Interviewer: Would you make an autistic person laugh?

**Thomas:** I have no idea....

Interviewer and Thomas: < laughter>

**Interviewer:** What do you find funny about autistic people?

**Thomas:** Well, some are very friendly and authentic. And, one of the things I love about them is they're so direct. I love when it's so direct because I know where I stand.

**Interviewer:** Mmm... Do you have any thoughts on the topic on the topic of the conference? You know, well-being, suicide prevention. Have you got any experience dealing with this stuff?

**Thomas:** I have struggled with a lot of mental health issues because I get a lot of anxiety from my social activity. And when I was little I was bullied a lot. But I feel like we never talked about it.

**Interviewer:** I mean, you know, the perspective that you then come into adulthood with is changed by those things.

**Thomas:** Yeah, yeah. As I get older, I am good at reminding me I am a good guy.

**Interviewer:** I mean, it must be quite different for you now because you've got, I mean, you have you must have quite a sense of purpose to have done all the things that you've done?

Thomas: Yeah

**Interviewer:** Where do you draw that strength from?

**Thomas:** I've always had so much, myself ... But I connect with so many good people. I'm surrounded by a lot of good people in my life.

**Interviewer:** Did you, do you think that you had the good fortune, or they were drawn to you, or like you sought them out or is all of those things?

**Thomas:** Its all of those things. I feel like because of my disability people tend to gravitate towards me more.

**Interviewer:** Right. So in a way, it's sort of a beacon?

**Thomas:** Yeah. I'm always glad because I love people.

Interviewer: Yeah. So you never lost a sort of sense of curiosity I guess?

Thomas: No

**Interviewer:** Do you think that is a guard against – do you think that's like – helpful, to good mental health? Actually feeling some optimism about other people?

**Thomas:** Yeah. So, if I'm home alone too much, it is no good for me [to have], so what I do is I go out and say hi to people. Because it makes me feel better about me.

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## **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)





**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