

Welcome everyone, and thank you for attending our webinar today.

We are excited to be presenting our autistic-led research priorities for autistic girls, women, and gender diverse people in Australia. Research has always been about us, instead of with us, and we are proud to be part of a project that has paved the way for future research for autistic girls, women and gender diverse people in Australia.

First of all, I'd like to do an acknowledgement of country. I acknowledge the Peerapper people of Lutruwita who are the traditional custodians of the land on which I'm coming from today, and I'd like to pay my respects to their elders past, present and emerging. I recognise their continued connection to the land and waters of our beautiful place and acknowledge that sovereignty was never ceded. It was and always will be Aboriginal land. I would also like to pay my respects to the activists, advocates and change makers, past and present for autistic people who have fought and still continue to fight for our rights, safety and equality.

I'd just like to let you all know that there'll be a Q and A session at the end, so please feel free to pop questions in the Q and A function at the bottom of your screen throughout the webinar, and then we'll be able to come to them at the end. We'll also be recording today's session and you would've received a little popup that mentioned that to you as you come in and the recording will be available later for you to access, both on the website that we'll be launching, that will have the video and the report there in the future, but also the link to the recording, will be emailed to you after the webinar. I'd like to hand over now to Rachel, to introduce our research team and give some background information about our research project.

Thanks very much Tess. I'm Rachel Grove. I'd also like to acknowledge the Awabakal people, the traditional owners of the lands that I'm on today. I'd love to start by introducing you to our research team. I'm a researcher from the University of Technology Sydney, and I've previously worked at the University of New South Wales and the Autism CRC. I'm also a clinical psychologist, with experience working with neurodivergent people and their families, particularly with autistic women, girls, and gender diverse people. I have a passion for and commitment to autistic-led and authentically co-designed research and I feel so privileged to be a part of this project and to have the opportunity to work with this incredible team.

Hayley Clapham is an autistic woman with a passion for participatory research and advocating for the rights, needs and interests of disabled people. Hayley has worked with the Autism CRC, the Autistic Self Advocacy Network of Australia and New Zealand, Women with Disabilities Australia, and held research advisory board positions at Macquarie University and the University of Queensland. She's currently studying a Bachelor of Psychology and working as a research assistant at Macquarie University.

Tess Moodie is a disabled, autistic, queer First Nations person and passionate advocate in LGBTQIA+ and disability rights and the prevention of violence against women, girls, and gender diverse people with disabilities. Tess also works for Engender Equality Tasmania, supporting survivors of family and sexual violence to engage in media, public speaking and legislative change.

Gabrielle Hall has a professional background in mental health and community nursing and is also trained in holistic health. Gabrielle is currently a research assistant and consultant for autism academic research and private research organisations. She's also a board director for Amaze and is in her second term as a member of the Victorian Disability Advisory Council. Gabrielle is an autistic parent with two neurodivergent children. Sarah Gurrin is an autistic ADHDer, that runs a private practise on the Gold Coast. Having previously been a primary school teacher, she predominantly

works with children age four to 14 years. Sarah has a special interest in working with girls, women, and gender diverse people. We would also like to acknowledge Dawn-Joy Leong as well as previous advisory group members who contributed to the initial stages of the project, and we'd also really like to thank everyone who shared their stories and insights as part of this research and other autistic advocates who are fighting for the rights of autistic women, girls and gender-diverse people in Australia.

Now I'll provide some background information about the project.

Why is this research important?

We know that autistic women, girls, and gender diverse people experience health inequities, such as shorter life expectancy, increased risk of suicide, more physical health problems, increased mental health conditions, and more sexual violence. They also have additional needs related to health and wellbeing, including sexual health, pregnancy and childbirth and periods and menopause. However, despite this, they report more barriers to accessing services and are underrepresented in research. So, we need urgent research that meets the needs of autistic girls, women and gender diverse people.

We know that research priorities have traditionally been set by researchers, parents, or health professionals. There is a need to preference the voices of autistic people, especially those who are less represented in research. While recent efforts have included the perspectives of autistic people, we wanted to develop a fully autistic led and informed research agenda. Young people have also been left out of the conversation, or considered too young to provide their own perspectives. It was really important that this study was co-produced and autistic-led. This means that autistic people were included from the outset and at all stages of the research project. An autistic advisory group was formed at the beginning of the project and they formed an integral part of the research team. All of our interviews throughout the project were also conducted by an autistic woman. So, we aimed to ask autistic girls, women and gender diverse people age seven and above, about their priorities for research. This included cis women and girls, transgender and non-binary, gender diverse people, and anyone who was socialised, or identifies as a woman, or girl.

There were two stages to our project. First, we conducted in depth interviews with 31 adults and 16 young people, aged between 7 and 63, and we asked them about their experiences, needs, and preferences for research. We used this information to develop 11 draft priority areas for adults and six priority areas for young people, and these also included a number of sub themes under each broad research area. So, this draft research agenda was used in the second part of the project, in which we surveyed 330 adults and 81 young people to get their feedback on these draft priority areas, and they were also asked to indicate whether there were any additional research areas, they thought were important. These responses were then further refined by the autistic advisory group, until a consensus was reached on the research priority areas for autistic adults and young people. And an autistic young person was also part of developing the final priority areas for young people.

At the outset, we aimed to capture people from a range of backgrounds and identities. Despite this, the majority of people we spoke to, were from a white European background, with high levels of education as well as people without intellectual disability and who used spoken communication. However, our survey did capture the perspectives of people with intersectional identities, 73% of the autistic adults in our survey, identified as being part of another marginalised group. 51% were from the LGBTQIA+ community, 26% were from rural regional areas, 9% were from a culturally and linguistically diverse background, 6% were migrants and refugees and 3% were First Nations people.

80% of the autistic young people in our survey also identified with being part of another marginalised group. Almost half were from the LGBTQIA+ community, 31% from rural or regional areas, 14% from a culturally and linguistically diverse background, and 7% were First Nations people. So, I'd now like to hand back to Tess to take us through some of the findings from the project.

Thanks, Rachel.

Now we're going to share with you the research priorities that we identified as part of our project and to lead into us presenting some more detailed information on this, we have a lovely little video that has been developed by Emma from Rowland Studio, that we'd like to play for you all.

[Narrator]

Autistic girls, women and gender diverse people experience more physical and mental health challenges, have a shorter life expectancy, experience very high rates of sexual violence and are up to nine times more likely to die by suicide. We need urgent research and support that meets our needs.

Research has always been done about us, instead of with us. This needs to change. We are paving the way for change when it comes to research about autistic people in Australia. For the first time, our research agenda has been led and informed only by autistic people.

We interviewed 47 autistic girls, women and gender diverse people age seven and above, about what research they think is important. We then surveyed an additional 411 autistic people for further feedback on our research priorities. We used this information to develop an autistic-led research agenda for autistic girls, women and gender diverse people in Australia. Six key research areas were identified by autistic young people. Better understanding and support at school. Understanding our experiences, strengths and challenges. Autism specific mental health support. Autistic friendships and relationships. Experiences of gender diversity and accommodations to make life easier for us.

Eight key research areas were identified by autistic adults including, Understanding and supporting specific needs in adulthood. Experiences of trauma, abuse and sexual violence. Supporting mental health and wellbeing. Addressing barriers in healthcare. Understanding and supporting physical health needs. Addressing barriers and education in the workplace. Understanding the role of society, embracing neurodiversity and the importance of autistic identity and Co-designing research and supports with autistic people and ensuring intersectional identities and harder to reach groups are included. It is critical that future research focuses on these priorities. We are making a direct call to action, by asking you to commit to research based on the priority areas and ensure your research is autistic-led, or co-designed. Your action will ensure that autistic girls, women and gender diverse people, can live their best lives.

Thanks again to Emma from Rowland Studios for working with us on developing that video. I'd now like to just take us through some more detail on the research priorities that were included in that video, and I'll start by talking about what young people told us were the priorities for them.

So, for young people the demographics, we found that between 65 and 80% of autistic young people in this project identified as female. Between 19 and 25% identified as non-binary, or other gender identities. A larger proportion of people had an intellectual disability in the interview phase of the project, with more non-speaking people contributing to our survey. More than 75% of young

people had an additional mental health condition, and physical health conditions were noted in 30 to 56% of young people.

So, the biggest priority for young people was around school, being better understood and supported in school. And young people emphasised the importance of providing education for teachers about autistic girls and gender diverse people and understanding how the structure of mainstream school doesn't always work for them. Young people wanted research that's about understanding and accepting that people cope and learn in different ways and how they can be better supported in school, particularly in regards to sensory and self-regulation needs. This research priority is also related to understanding the experiences of bullying and also their different experiences of learning. And there's a couple of quotes there just on the screen that were taken directly from young people. This quote, we've pulled this one out because it sums up the research priority area really well: *"School should improve a bit on how much the teachers know about autism in general and neuro divergence, ADHD, all these different things, because it's very common and schools aren't always set up to help these kids, I think there could be quite a lot of improvement in the education system"*.

The second research priority outlined the need for research that is focused on understanding both the strengths and the challenges of autistic young people, and this priority highlights the need for research to understand sensory differences, the importance of stimming and self-regulation, as well as the experiences of puberty and physical health needs. It also related to the understanding, to understanding the impact of gender roles and stereotypes in society and the effect that this has on autistic girls and gender diverse young people. Throughout our research, we also heard stories about strengths: *"I think it's my ability to accept people for who they are. I think I'm a very genuine person and I can see people and I can very much see what they might be struggling with and what strengths they might have"*.

The third research priority outlines the need to support the mental health of autistic girls and gender diverse young people, and this includes understanding misdiagnosis, as well as the impacts of masking on our mental and physical health. There is also a need for research that aims to understand the role of social pressures on our mental health and how we can change mental health support to suit autistic young people. This quote describes the impact of these social pressures really well: *"There's a pattern at least of autistic people, girls in particular, crashing in their early teens sort of thing, because of having to deal with increased social pressures"*.

The fourth research priority area relates to the need to understand differences in autistic friendships and relationships. This includes different communication needs and social preferences. This priority area also highlighted common experiences such as feeling like you don't belong and the importance of friendships with other autistic people. This quote highlights the challenges that autistic young people face: *"I can get very stressed with too much social stuff, which is hard because I'm actually a very social person. I really like being around people. If I spend a lot of time with people, I have to take a few days to recover"*. That quote's even valid for us who aren't young people anymore.

The fifth research priority emphasises the need for research that focuses on acceptance and affirmation of gender diversity and the supports that autistic gender diverse young people may need to be supported to live their lives in their whole identity. This young person described the challenges of being supported as an autistic, gender diverse young person: *"Because there's an insanely high amount of gender diverse and LGBT people on the autism spectrum, my way of looking at it is focus on support first"*.

The final priority identified was about how to make life easier for autistic young people. This includes challenging what other people think autism is, as well as knowing what support autistic girls and gender diverse people need, including support across their lifetime and how to access this support. Young people also highlighted the need for changes to the diagnostic process, to ensure that autistic girls and gender diverse people are diagnosed and supported early. This priority area also highlighted the importance of including autistic people in the conversation, when it comes to research. Young people emphasised that being autistic is something to be proud of. This shows the need to change the world to fit us, rather than expecting autistic young people to adapt, something that has significant impacts on their health and wellbeing.

I'd like to hand over now to Hayley, who will present the research findings that we had for adults.

Hi. I will now provide some further detail on the research priorities identified by autistic adults. So, 80% of the autistic adults in our research identified as female, with 20% identifying as non-binary, or gender diverse. About 45% of the people that we spoke to, were also autistic parents. There were very small numbers of people with an intellectual disability and who did not use spoken communication. Mental health conditions were reported by 80 to 90% of people, and physical health conditions were also reported by 50 to 60% of people in this project.

So, the first research priority area identified by autistic women and gender diverse people was related to the need for research that aims to understand autism across the lifespan and develop support programs that are designed for autistic adults. This research priority area also indicated the need for research about the experiences and needs of autistic parents. Research is also needed that focuses on understanding the day-to-day challenges of autistic adults, as well as friendships, relationships, and experiences of homelessness and financial insecurity. Less than 30% of the adults we spoke to currently had access to NDIS funding. This highlights that there are many autistic adults not currently receiving support and the unaddressed barriers for autistic women and gender diverse people to apply for and receive NDIS funding. This quote sums up the first priority area well: *"It's like once you're out of nappies, no one's interested. No one wants to know about an autistic adult"*.

So, the second priority area highlighted the importance of understanding the experiences of trauma, abuse and sexual violence. There is an urgent need for research that focuses on how to support autistic women and gender diverse people who have experienced trauma, or who are victim survivors of the many forms of abuse and sexual violence. This highlights the need for trauma informed research and services that are co-designed with autistic people. This quote emphasises the systemic challenges that autistic women and gender diverse people deal with when reporting abuse, or getting supports: *"How do you prove child abuse? How do you prove spousal abuse, when no one believes you at the time? The whole system is intrusive and abusive"*.

The third priority area highlighted the need for research that is focused on supporting the health and wellbeing of autistic women and gender diverse people. This includes understanding misdiagnosis, autistic burnout and co-designing supports and therapeutic approaches that suit autistic people. The priority area also focuses on the importance of providing support for autistic people from a range of backgrounds and those with high support needs. Research needs to focus on developing autistic-led models of well-being in order to understand *"How to help autistic people have a good life on their own terms"*.

The fourth research priority emphasises the need for research into the health inequalities experienced by autistic women and gender diverse people and identifying areas for change. This

includes providing inclusive diagnostic practices and access to services. There is also a need for research into understanding the experiences of navigating the health system, including medical gaslighting due to the emphasis on the medical model of autism and the male bias within the system. These experiences were commonly reported in our research. This priority also outlines the need to develop education for healthcare professionals about the needs of autistic women and gender diverse people. This autistic adult spoke about their experience of navigating the healthcare system: *"Nine years of the same specialist and really it's only been in the last couple of years that he's starting to listen to some of the things that I have to say"*.

So, this research priority area outlines the importance of recognising and supporting the physical health needs of autistic women and gender diverse people. This includes sexual and reproductive health, pregnancy, childbirth, puberty, periods and menopause. This research priority also outlines the need for research into understanding co-occurring physical health conditions including how physical health conditions may present differently. This quote sums up a common experience that was described by autistic adults in our study: *"I've got so many things wrong with my body and I just do my best to keep on going. I just do my best to keep functioning"*.

The six priority area identified the need for research that aims to understand and address barriers within the education system and the workplace. Autistic women and gender diverse people spoke about their experiences in a range of education settings from specialist schools to the tertiary system. This priority area also emphasises the barriers to obtaining and in maintaining employment. 65 to 70% of the people we spoke to were employed, which highlights the challenges of autistic people in finding and maintaining employment. There's also a need to understand how to provide support in education in the workplace, as well as how teachers and employers can be educated about assisting autistic women and gender diverse people within these systems. As one adult stated: *"The infrastructure isn't there, or the education isn't there. It really is massive issue of equality and equity and I just think, I feel, I'm always just hanging onto my job and the only way I can do it is to play the part"*.

The next priority area outlines the importance of understanding the impacts of stereotypes and gender roles in society. This results in the daily experience of trauma for autistic women and gender diverse people, which they describe as being due to *"living in a world that's pretty much not about us"*. This research priority also focuses on celebrating and supporting the strengths and the importance of autistic identity and community. This quote highlights the importance of providing research that is from the perspective of the neurodiversity paradigm: *"Research into how you assist autistic people to deconstruct a life that was constructed by neurotypicals and then use a different framework to actually allow them to construct a life that's actually based on their values"*.

The final priority area highlights the need to provide research from an autistic perspective. This needs to be from the perspective of all autistic people, including people with intersectional identities, harder to reach groups, and with different support needs. This priority area also emphasises the need for supports and services to be co-designed with autistic people. This quote sums up this priority area and how all research with autistic people should be conducted: *"We need more research on understanding it from the autistic perspective rather than layering non-autistic perspective over the top because it's so deficit based"*.

How we hope these findings will be used.

As we have mentioned, one of the priority areas is around co-designing research and supports with autistic people and prioritising the voices of people with intersectional identities, those from harder

to reach groups and with different support needs. Even in our own research which attempted to prioritise these voices from the start, some autistic people were still made to feel invisible. This needs to change. We need research that focuses on the needs of autistic women with high support needs, research into the specific issues based by multiply marginalised people, being in a rural community and the impact that has on autistics.

We need to change our research culture, so that all autistic people can feel included and prioritised by research. This means working with these communities and designing research that meets their needs. This means changing our research methods to be more accessible to people with an intellectual disability and to non-speaking autistic people. We need to also move away from the deficit medical model, to understand autism from the social model of disability and the neuro diversity paradigm, to challenge the systems that support them. There is also a need to focus more on the areas of research that are important to the autistic community and will have a direct and positive impact on their lives.

As demonstrated in the video, we're again making a call to action to ask you to join us, in improving the quality of life of autistic girls, women and gender diverse people. To enable this to happen, it's absolutely vital that you make some commitments. We are asking you to commit to research that focuses on the priority areas that are identified, by the autistic people that we spoke to and ensure that your research is autistic-led, or authentically co-designed. Unless future research is guided by these principles, it will continue to fall short of what autistic people need. Your action will ensure autistic girls, women, and gender diverse people can be understood and supported to have a good life on their own terms.

So, we wanted to end this webinar with a video from a young autistic person who was involved in developing the research priorities for autistic girls and gender diverse people.

Hi, my name's Violet and I am a 16 year old autistic girl. People are often surprised when I say this, but I promise it's true. That's a metaphor that I've had a lot of autistic people use to describe what it feels like to be autistic in a mainly neurotypical allistic world. "Autism can make you feel like you've been thrown into a game where everyone is running around and making seemingly arbitrary moves and people are expecting you to know how to play, but you never got a rule book". Now, if that metaphor made absolutely no sense to you, don't worry, it didn't to me the first time either. Metaphors by and for autistic people don't always go as planned, but after some research and a consultation with some of my finest neurotypical friends, I have deduced that basically it means that the world is very, very, very confusing. But hopefully with the help of some nuance research, with empathetic but still unbiased people, unbiased people is one of my favourite paradoxes, we can make this game a little less confusing.

People often assume that autism looks a certain way, and one of my biggest hopes for the future of autism studies is that we acknowledge the many different ways that autism can present. In girls and gender diverse people, autism often shows in a way completely unheard of, to the general population, and until recently, most of if not all experts as well. When autism was first discovered, it was discovered simultaneously by Leo Kanner and Hans Aspergers. I won't bore you with all the details of the history, because once I start talking, I will not stop. Psychology and autism is my special interest, which is convenient. Asperger basically insisted that the young boys he studied were smarter than a lot of the other mentally disabled people at the time, and that he could not find evidence of this particular disorder in anyone except for boys. And Kanner was convinced only four in 10,000 boys, no girls, presented with what he called true infantile autism. In short, both were wrong, and lots of these myths still exist today. Though, through more detailed and well-

documented research, I hope that these myths can be replaced with genuine, provable facts, that will ultimately benefit the huge autistic population.

Throughout history, autistic people have merely been the subjects of the studies that decide how we'll be treated, and I'm so excited that this is changing. Being autistic teenager, at least in my experience, means that you can feel incredibly frustrated all of the time at how the world responds to your existence, and it's hard to see any way forward. I have hope that the more research being done into how best to support me and people like me will accelerate the movement to not just the acceptance of neurodivergence, but the celebration of it. That's something that's very important to me and many other people on the spectrum, that we are not treated as burdens. This isn't to say that autism doesn't come with challenges and struggles, or that it will ever be rid of those challenges and struggles. I know it does. I know it will. Trust me I do. I live in a world that isn't designed for me. Some days waking up and getting out of bed can feel like running a marathon. But it's because of our autism in this world, that we can have people run actual marathons in record breaking times, and people form deep connections to those around them.

We are sparkling, unique and wonderful variations in the human race, that have given so much to this world, from kindness and passion to the theory of relativity and Olympic gold medal winners. We are doctors and teachers and builders and parents and librarians and the old woman across the street whose house is covered in flowers because she spends all day, every day watering them and taking care of them because it makes her happy. This is what researchers need to know. With the help of our loved ones, disability aids and a more inclusive world, we can flourish and live incredible happy lives.

We just want to say thank you to Violet for creating and sharing that video with us.

So, thank you everyone for coming along today to our launch. It has been really clear from our research that autistic girls, women and gender diverse people, know exactly what they need, not to only survive, but to thrive. Women with disability often have removal of our agency, decision making or input into their own lives and how they need to be supported. Often decisions are made about us, or for us. And using collaborative research to set priorities with us, instead of for us, paves the way for validating autistic women, girls, and gender diverse people, to be able to take control of where the future research is directed, and subsequently how we are supported based on what we need as a neurodivergent person, who has insights and strengths, not just using the medical model, which often focuses on treating and fixing us, instead of supporting us holistically, and ensuring we can flourish in a world that was not made for us.

For more information, you can go to the website that we will have live very soon, and the website address is in the slide, on the screen. Or you can also email us at the email address in the slide as well. Everybody that's here today, even those that registered and didn't quite make it into the webinar, will receive an email with those links and contact information. We'll be working on a full report about our research findings sometime in the near future. We will be releasing this and we'll also email a copy of this to everyone who has attended the webinar today, and that will also be available on the website that we have on the screen once that's finalised.

Once again, we would like to thank you all for coming along today and we would like to sincerely thank everyone who shared their stories and insights as part of this research, and some of you are in the room today. We'd also like to thank other autistic advocates who keep fighting for our rights as autistic women, girls, and gender diverse people in Australia. Thanks again for coming. Have a great day.