

# Highlighting the voices of autistic girls, women, and gender-diverse people in Australia

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## 1. Summary of impact

This project is the first-ever autism research agenda to be developed based solely on the voices of autistic girls, women and gender diverse people. It places a list of clear, actionable autism research priorities into the hands of academic, clinical and community researchers across Australia, opening the door to a new generation of research that reflects the lived experiences, needs and aspirations of the autistic community.

## 2. The problem

The voices of autistic people, particularly those who are female or gender diverse, are often lacking in research intended to represent their interests. In part, this is because autism was historically considered as something more commonly seen in males. In addition, research has prioritised the voices of families and health practitioners over autistic people themselves. Autistic girls, women and gender diverse people also experience physical and mental health challenges, very high rates of sexual violence and are up to nine times more likely to die by suicide. Centring the experiences of girls, women and gender diverse people in autism research is crucial to addressing these issues.

### **3. Beneficiaries**

This work has the power to deliver significant benefits to autistic girls, women and gender diverse people who, for the first time, will see their needs reflected in contemporary autism research. It also provides researchers with an evidence-based research agenda that can guide the development of their work, enabling the creation of new knowledge that is meaningful not only to autistic people but to their families, support people and health care teams.

### **4. Approach to impact**

The research team embedded the autistic experience at the heart of this project. While developing the research agenda, they established a working group comprised of autistic parents, professionals, and advocates to ensure that this research reflected the needs of the autistic community. The resulting research agenda is based on interviews with 47 autistic girls, women and gender diverse people aged seven and up. It captures two distinct sets of research priorities — one for adults and one for young people.

The UTS Social Impact Grant funded a review of the draft research agenda within the autistic community. Three hundred and thirty adults and 81 young people provided feedback on the draft that was incorporated into the final document. This funding also enabled the dissemination of the research agenda via the development of a video, a one-page infographic report, a website, and an online launch, making it widely available to researchers, clinicians, community organisations and autistic people in Australia and beyond. The agenda is now freely available to the global research community via the UTS website.

### **5. What has changed as a result of this work?**

This project empowered autistic women, girls, and gender diverse people to play a key role in shaping autism research now and into the future. Autistic members of the research team included autistic parents, disability advocates, a psychologist and gender-based violence advocates and included both autistic women and non-binary people. This group worked collaboratively and have continued to collaborate on autism-led research since the completion of this project.

## 6. What has helped you accomplish this work?

The autistic working group that guided the development of the research agenda, as well as its dissemination, are the soul of this project. Their contributions allowed this research to be driven by the autistic community and for autistic girls, women and gender diverse people's insights and experiences to sit at the heart of the research agenda. Funding from the Social Impact Grant was critical in enabling the research to be disseminated to the community and in paying the working group participants who generously gave their time.

## 7. Challenges

The research team struggled to access a diversity of autistic voices to help shape the research priorities captured in the agenda. This is a challenge common within academic research, which often prioritises rigid engagement and data collection processes and seeks lived experience representation via channels that often favour white, well-educated contributors rather than reflecting the full diversity of the community. The researchers are now working with a range of autistic people and looking for new ways to engage with a broader segment of the autistic community to lead future projects.