

Community insights and unheard perspectives:

Recommendations for inclusive community engagement in the National Autism Strategy

Executive Summary

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Autism CRC

Autism CRC is the independent national source of evidence for best practice in relation to autism across the lifespan and the spectrum.

We provide the national capacity to develop and deliver evidence-based outcomes through our unique collaboration with autistic people, families, professionals, services providers, researchers, and government. Together, we are addressing agreed needs and co-producing outputs with these stakeholders for the benefit of the community.

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A note on terminology

We recognise that when referring to individuals on the autism spectrum, there is no one term that suits all people. In our published material and other work, we use the terms 'autistic person', 'person on the autism spectrum' or 'person on the spectrum'. The term 'autistic person' uses identity first language, which reflects the belief that being autistic is a core part of a person's identity. Autism Spectrum Disorder (ASD) is diagnostic terminology used by the healthcare sector and is used in the context of a person being 'diagnosed with Autism Spectrum Disorder'.

Why we did this work

The Australian Government aims to develop a National Autism Strategy that meets the needs of all autistic people. The development of the National Autism Strategy must involve a wide range of stakeholders from diverse backgrounds including the groups whose voices and perspectives often remain unheard. This work aimed to identify these groups and determine appropriate methods for engagement in the Strategy consultation.

What we did

A co-design process was implemented through five phases: Research, Problem definition, Solution ideation, Idea validation and testing, and Delivery. The phases of the co-design process, and methods employed, were:

- established an autistic advisory group and defined target groups (n=5) – research phase
- autistic-led literature and environmental scan on best practice community engagement and target group definitions and key considerations - research phase
- co-produced Community views national survey (n=645) - problem definition and solution ideation phases
- co-delivered workshops and interviews with autistic individuals (n=25), representatives from peak bodies, autism and/or disability organisations (n=13) and autistic representatives from autistic-led organisations (n=4) - problem definition, solution ideation and, idea validation and testing phases
- co-produced Community engagement plan – delivery phase.

What we found

Explored through the co-design process, the data showed significant overlap between the various methods employed to define and understand the groups that require a tailored or adapted approach to actively participate in the development of the National Autism Strategy.

These groups were determined as autistic people who are also: First Nations; from culturally and linguistically diverse backgrounds including migrants and refugees; LGBTIQ+; have an intellectual disability; live in cared or supported accommodation; live in rural and remote communities; have experienced incarceration; have experienced homelessness; people whose primary method of communication is not spoken language; ageing and ageing carers of autistic people and; children and young people.

The literature, problem definition, solution ideation, idea validation and testing phases of the co-design process garnered clear recommendations for inclusive community engagement. These are:

- written information should be readily accessible and conveyed in easy-to-understand language, such as easy-read or plain English, accompanied by visual aids

- ensure communications about the National Autism Strategy and opportunities for engagement are not wholly reliant on access to technology
- work through and with organisations that have longstanding and trusted relationships with various community groups
- allow adequate time for people to prepare, process information and respond meaningfully
- consider the information and stories that have already been shared during other government consultations
- facilitate individuals' understanding of the direct impact of their contributions or how their input can lead to positive change
- ensure topics of distress and trauma are treated with the highest level of sensitivity and compassion, with options for follow-up support
- ensure meaningful involvement of autistic people with diverse cultural backgrounds and life experiences in decision-making processes, consultations and activities
- foster a culture of equity and transparency, recognising and valuing all contributions, and ensuring confidentiality is maintained
- facilitate engagement through diverse methods and platforms, allowing individuals to select an approach that aligns with their needs and preferences
- ensure that community engagement processes consider culturally appropriate questions about the intersectionality and attributes of various stakeholders
- ensure that community engagement processes consider the importance of capturing the diverse backgrounds and experiences of autistic people.

Next steps

The community insights and recommendations established through this body of work have informed the development of a Community engagement plan which outlines the process for involving all stakeholders in the development of the National Autism Strategy. These findings highlight that there is no 'one-size fits all' approach to the promotion of, and engagement in, co-design and consultation. Further, they emphasise the importance of an inclusive approach, enabling people to engage in ways that suit their individual needs and preferences – to ensure all voices and perspectives have equitable opportunity to be heard.

Our values



Inclusion

Valuing lived experience



Innovation

Solutions for long term challenges



Evidence

Truth in practice



Independence

Integrity through autonomy



Cooperation

Capturing opportunities together



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