Are you an individual or making a submission on behalf of an organisation?

Organisation

Organisation name

Autistic Self Advocacy Network of Australia and New Zealand

Is your organisation....?

- A peak-body
- Research, academic or advocacy organisation

What type of service or support do you mostly provide?

- A national program and/or information service

What state or territory does your organisation deliver services and supports in?

- New South Wales
- Victoria
- Queensland
- Western Australia
- South Australia
- Tasmania
- Northern Territory
- Australian Capital Territory
- Western Australia

Where does your organisation deliver most of their services and supports?

Prefer not to say

1. Does the new vision reflect what we all want for children and families?

Yes.

2. Are the two main outcomes what we should be working towards for children and families? Why/Why not? - Outcome 1: Parents and caregivers are empowered

to raise healthy, resilient children - Outcome 2: Children are supported to grow into healthy, resilient adults.

No.

Focusing on "health" in the outcome makes sick and disabled children and their families feel othered. It is not an inclusive outcome.

Outcome 1: Parents and caregivers should be empowered with skills, confidence and connections to:
* support their childrens development
* nurture healthy relationships with their children
* provide safe and inclusive environments

Focusing on resilience and health as an outcome others disabled, sick and vulnerable children. It doesn't respect the child's own agency to decide, for example, that their mental health takes priority over their physical health, or to prioritise vulnerability over resilience. Focusing on resilience has the potential to encourage autistic children to mask, or hide thoughts that aren't aligned with the outcomes. These are children that are already at increased risk of suicidal ideation, and death by suicide.

Outcome 2: Children are supported to develop into their best selves.

3. Will a single national program provide more flexibility for your organisation?

No

4. Does the service or activity you deliver fit within one of the three funding streams? Do these streams reflect what children and families in your community need now – and what they might need in the future?

No. We provide national support (self advocacy resources, systemic advocacy, etc) for a targeted cohort that is hard to reach.

The suggested approach to funding leaves us without any funding opportunities to support Autistic parents and family members to find their community and self-advocate.

Evidence shows that autistic people experience trauma and adverse experiences differently to others, and are greatly increased risk of Adverse Childhood

Experience (ACEs) than their peers. The lifetime impacts and costs associated with a high number of ACEs is well documented and includes (but is not limited to):
- reduced levels of education
- reduced levels of employment
- lower family income
- increased mental health and health issues
- shorter life expectancy
- increased risk of physical and sexual abuse

Providing autistic and neurodiverse parents with supports from their PEERS is an unmet need.

5. Are there other changes we could make to the program to help your organisation or community overcome current challenges?

Yes

Redefine tier 3
1. Change Intensive to Complex
2. Add "Ethical" to "Evidence-informed" (for example: evidence-informed reduction in observable behavioural traits that lead to diagnosis for a neurodevelopmental identity not being given, even though that person has that neurodevelopmental profile is not ethical)
3. Add all adverse childhood experiences to the list of things at risk.

Revised Tier 3
Complex family supports
Ethical evidence-informed services that support children at risk of adverse childhood experiences.
Support for families facing multiple, complex challenges – offering tailored help to meet their specific needs.

6. Do you agree that the four priorities listed on Page 4 are right areas for investment to improve outcomes for children and families?

Point 3 needs to go beyond being "informed" by.
To achieve the vision and outcomes, genuine partnership and co-design is needed.

7. Are there any other priorities or issues you think the department should be focusing on?

Being able to acknowledge that:
* the way things have been done, isn't always the best or right way.
* they can learn from others, even if they don't agree or are less qualified.
* informing and consulting do not deliver outcomes that are valued by vulnerable and hard to reach communities
* they are going to be uncomfortable - it's not vulnerable, disabled or marginalised people's jobs to make them comfortable - it's their job to listen and learn from things that are hard to hear
* looking for individual self advocates that align with their own policies and views is NOT partnership with the community
* solutions won't always be simple for them to understand - as a neurotypical person, they won't communicate or understand things in the same way a neurodivergent person will. It's ok to not feel superior or understand everything - welcome to our world!
* inclusion is a mindset and everyone's responsibility - it's not a separate department that provides insight reports and thematic analysis. (just like safety is everyone's responsibility)
* building a "one size fits most" program and then trying to bolt on extras isn't inclusion.
* consulting on inclusion with a specialist agency that isn't run, led and owned by the people you are trying to include is taking funding away from the people you are trying to help. Stop it!
* pay for advice and consultation activities in the same way you pay consultants like KPMG - stop using not for profits as slave labour - paying for a 1 hour consult that uses up a day of our capacity is Modern Slavery.

8. Do the proposed focus areas – like supporting families at risk of child protection involvement and young parents match the needs or priorities of your service?

No - this needs to be extended to all events that are known to result in Adverse Childhood Experiences. This includes:
* a parent with a mental health condition
* death of an immediate family member
* risk of homelessness
* risk of poverty

9. Are there other groups in your community, or different approaches, that you think the department should consider to better support family wellbeing?

We encourage the department to consider (free!) programs such as RIE and Visible Child, to provide judgement free, trauma-informed, respectful, developmentally appropriate, evidence-informed supports to parents of infants. These are programs that can be accessed online or in community groups, that provide skills and support through from birth through to adulthood.

Balanced advisory groups that include people (more than 2) with lived experience of being the children the program (element) seeks to support is vital. These advisory groups should consider the research and tools currently being developed by organisations such as ASAN AUNZ (Autistic Advisory Groups Guide and Toolkit due for release in June 2026) and University of Southern Queensland's Inga Koops' associated research that is currently in progress.

10. What are other effective ways, beyond co-location, that you’ve seen work well to connect and coordinate services for families?

Ways we've seen work well to connect and coordinate services for families for autistic and neurodivergent communities integrate the following:

1. Peer networks. Many, if not most, people in our community do not trust recommendations or referrals from people who are neurodivergent.

2. Virtual and hybrid options, that don't prioritise face to face. Many autistic people have co-occurring conditions that make attending in person challenging, and because of the dynamic nature of autism, these challenges might only show up on the day. It's important that autistic people aren't made to feel less or othered by not being able to attend or connect in the same ways as neurotypical people.

3. Value and cater for all forms of communication: Ensure all online forums have at least 4 facilitators - the speaker, the chat monitor, the helper and interpreters. They need to have chat and captions enabled, ideally with live captioning.

4. Respond to individual supports and accessibility needs: If there are online meetings, be sure that a calendar invitation with the link is sent so the person isn't searching their emails at the last minute. Provide all reference materials, agenda, etc in ONE location. If minutes or actions are being taken, add another facilitator that actually attends the meeting and doesn't just see the transcript and AI outputs, and send the outputs within 3 days of the meeting.

5. Connect the coordinators directly, so they build their own community networks. Don't try to control the outcomes or the communications. If processes set this up,

there are always people who want to gatekeep - even with the best of intentions.

These should be the minimum standards.

11. What would you highlight in a grant application to demonstrate a service is connected to the community it serves? What should applicants be assessed on?

Applicants should be assessed on:

* ability to deliver services that are valued by the community is serves

* being owned, led & operated by (qualified & experienced) people who are part of the community it serves

* being an organisation that is trusted by the community serves (not the general community or the person assessing the grant application!)

* whether the grant funds will be used to pay other people or businesses who are part of the community it serves

* whether the community to be served can access the organisation's services in ways that are safe, inclusive and accessible for them

12. Beyond locational disadvantage, what other factors should the department consider to make sure funding reflects the needs of communities?

Autistic communities have many factors to be considered beyond locational disadvantage, these include (but aren't limited to):

* Diverse Communication Styles and Needs: AAC, Auslan, Written, Supported Decision Making, Easy Read, Visual, Systems thinking, etc

* Intersectional identities, experiences and conditions: LQBTIAQSB+, First Peoples, Intellectual Disabilities, Survivors/Victims of Sexual/Physical/Domestic Abuse/Violence, Mental and Physical health conditions (eg POTS, EDS), other neurodivergent identities (eg ADHD, dyslexia, etc), unemployment, homelessness, etc.
Many autistic people have multiple

* Complex needs: Many autistic people have other sensory processing issues and neurodevelopmental challenges that the general population isn't aware of and

often dismisses or minimises. This includes things like Rejection Sensitivities, Demand Avoidance, Avoidant/Restrictive Food Intake Disorder (ARFID), Auditory Processing challenges,

13. What's the best way for organisations to show in grant applications, that their service is genuinely meeting the needs of the community?

Feedback from the community - not neurotypical parents commenting on their autistic or neurodivergent children or spouses.

Wellbeing of the community - long term mental health outcomes for neurodivergent people - not the comfort of or observations by neurotypical family members. (eg evidence shows that autistic people are unlikely tell them they are thinking about self-harm)

Number of people from the community engaged in delivering the services, as well as receiving the services. Percentage of funds paid to community engaged in delivering the services.

14. How could the grant process be designed to support and increase the number of ACCOs delivering services to children and families?

Support us to connect and partner with ACCOs.

15. What else should be built into the program design to help improve outcomes for Aboriginal and Torres Strait Islander children and families?

Genuine co-design with ATSI children and families. Particularly those in the cohorts being targeted (eg Autistic Aboriginal parents)

16. What types of data would help your organisation better understand its impact and continuously improve its services?

ABS reporting in line with UN (UNCRPD and UNCRC) definitions and requirements. NDIA releasing a de-identified data lake that enables us to deep dive into where services are being delivered, but also identify where they aren't (thin markets), so we can focus on these.

17. What kinds of data or information would be most valuable for you to share, to show how your service is positively impacting children and families?

Our most valuable information on positive impact comes from conversations and connections built with our community.

They say things like:
- they've finally found people who understand them after a lifetime of loneliness.
- thank you for not telling us how to do it but working with us to find the way
- your tools are so valuable, can I share them with others?
- if it okay if I translate your materials for my community?
- can we partner with you to co-design with our shared community?
- we value what you do so much
- how can I help you do more?
- you've helped me feel better about myself and where to go from here

The best data we could see would be:
- reduced rates of death by suicide and suicidal ideation in autistic people
- reduced rates of physical, domestic and sexual abuse/violence against autistic people
- improved employment rates for autistic people

and similar data for other areas where autistic people aren't served as well - education, justice, health, community, politics, government, etc.

18. If your organisation currently reports in the Data Exchange (DEX), what SCORE Circumstances domain is most relevant to the service you deliver?

N/A

19. What kinds of templates or guidance would help you prepare strong case studies that show the impact of your service?

Templates and guidance materials co-designed with autistic people.

20. What does a relational contracting approach mean to you in practice? What criteria would you like to see included in a relational contract?

Please consider the recommendations of World Commerce and Contracting (WorldCC.com) and answers to earlier questions on this topic.

21. What's the best way for the department to decide which organisations should be offered a relational contract?

Offer it and see who's interested.

22. Is your organisation interested in a relational contracting approach? Why/why not?

Yes - because it provides better long-term outcomes.

23. Is there anything else you think the department should understand or consider about this proposed approach?

Please also consider the framework set out in ASAN AUNZ's submission to the Thriving Kids inquiry. https://www.aph.gov.au/DocumentStore.ashx?id=898cfd7b-42c6-47da-afc9-e2463b99854a&subId=779069