



23 September 2024

Autism and Health Roadmap Working Group  
C/o Department of Health and Aged Care  
GPO Box 9848  
CANBERRA ACT 2601

Submitted via email: [AutismRoadmapConsultation@health.gov.au](mailto:AutismRoadmapConsultation@health.gov.au)

Dear Working Group,

**Amaze submission to draft National Roadmap to Improve the Health and Mental Health of Autistic People.**


Amaze works to build acceptance and understanding of autism in communities, educational settings, organisations and businesses, and wider society. Informed by evidence, experts and lived experience, we influence policy change for Autistic people and provide independent, credible information and resources to individuals, families, professionals, government, and the wider community. We are closely connected with the community through our national Autism Connect helpline, peer support networks and capacity building initiatives.

We are pleased to provide the attached submission to your draft National Roadmap to Improve the Health and Mental Health of Autistic people.

Please contact me by email at [david.tonge@amaze.org.au](mailto:david.tonge@amaze.org.au) or by phone on [03 9657 1600](tel:0396571600) if we can assist by providing further information or answering any questions you may have.

Yours sincerely,

David Tonge  
Acting Chief Executive Officer



Amaze submission to draft National Roadmap  
to Improve the Health and Mental Health of  
Autistic People.

23 September 2024.



## Executive Summary

We welcome the draft *National Roadmap to Improve the Health and Mental Health of Autistic People, 2025 – 2035* (“Roadmap”). The proposed Guiding Principles, Focus Areas and Possible Actions comprehensively address many of the complex barriers to healthcare faced by Autistic Australians and (if implemented in full) have the capacity to significantly improve their health and mental health outcomes.

To strengthen the capacity of the Roadmap to meet the vast and complex health and mental healthcare needs of all Autistic people our submission recommends that the Roadmap identify firm commitments and drive a whole of governments approach. It also recommends that the Roadmap specify targeted actions to: improve the health and mental health of priority cohorts; prioritize preventative health and health promotion; comprehensively address suicide prevention; prevent, identify and treat co-occurring eating, alcohol and drug use disorders; and promote the availability of specialist service options.

### Summary of Recommendations.

- Develop the Roadmap (and National Autism Strategy) as a whole of governments initiative, and/or link to Australia’s Disability Strategy to drive service integration, national consistency and collaboration, and comprehensive accountability measures.
- Amend each of the ‘Possible actions for Focus Areas’ sections of the Roadmap to include sub-sections identifying targeted actions that specifically address the needs of priority cohorts.
- Extend current consultation timeframes to ensure Autistic people (and families and carers) from priority cohorts can inform targeted actions and the Roadmap’s broader development.
- Link the Roadmap and National Preventative Health Strategy.
- In the Guiding Principles, highlight the importance of understanding and promoting the needs of Autistic individuals in preventive healthcare and health promotion programs, policies and initiatives.
- Specify actions to fund annual health and mental health checks for Autistic people.
- Review health promotion initiatives and information resources to ensure they are accessible for Autistic people.
- Ensure the Roadmap comprehensively addresses suicide prevention for Autistic people, and links to the National Suicide Prevention Strategy and National Suicide and Self Harm Monitoring System.
- Specify actions to prevent, identify and treat eating disorders that commonly co-occur with autism, including anorexia, ARFID and pica, and drive clarity regarding service system responsibilities.
- In the Guiding Principles, highlight the service needs of Autistic people with alcohol and drug use disorders.
- Specify actions to co-design training and guidance for health practitioners on preventing, identifying and treating alcohol and drug use disorders among Autistic people, and drive further research into understanding and addressing alcohol and drug use disorders among this cohort.
- Identify specific actions in Focus Area A to review and co-design information resources for health professionals, Autistic people and their families and cares about specialist service options.

## Introduction.

We commend the work undertaken so far to develop a draft Autism Health Roadmap and welcome the proposed Guiding Principles, including the recognition of priority cohorts in need of targeted interventions and support. We also welcome the proposed Focus Areas and Possible Actions, particularly actions to co-design a framework for Autism Affirming Care, drive more accessible information, resources and autism friendly spaces, require autism proficient service navigators/liaison officers, create a competency-based national program of professional development, strengthen research and data collection, and prioritise inbuilt accountability measures. We agree that together, these actions have the capacity to significantly improve the health and mental health of Autistic Australians. Implementation timeframes and a robust monitoring, evaluation and reporting framework will be crucial to ensuring the Roadmap's effectiveness and transparency.

To ensure the Roadmap has the capacity to meet the vast and complex needs of all Autistic people, our submission recommends that consideration be given to how the Roadmap can drive firm commitments and enhanced national consistency and service integration. We also recommend actions that specifically target priority cohorts, improve awareness of specialist services options, prioritise preventative health and health promotion, comprehensively address suicide prevention and address eating, alcohol and drug use disorders.

### 1. Provide firm commitments and drive service integration.

We are concerned that the Roadmap provides "Possible Actions" only when firm and comprehensive commitments are urgently needed. The health and mental health outcomes of Autistic Australians will not be meaningfully improved by the implementation of only some of the possible actions identified, each of the actions must be implemented to drive real change.

In its Final Report, the Senate Select Committee on Autism clearly envisaged a whole of governments approach to better integrate federal and state service systems, including NDIS and mainstream services. Accordingly, in our recent submission to the draft National Autism Strategy, we encouraged the federal government to advocate for the Strategy to become a whole of governments initiative to drive national consistency and collaboration, as well as State and Territory autism commitments and the development of State and Territory autism plans. We similarly encourage that the Roadmap functions as a whole of governments initiative to drive national consistency and collaboration, and improve service integration. The need for a whole of governments approach has never been higher, with the need to ensure Foundational Supports play a key role in improving autism accessibility and inclusion across health and mental health services across Australia.

At the very least, the Roadmap (and National Autism Strategy) should link to Australia's Disability Strategy to ensure an autism lens is applied to how it may improve service integration for Autistic people, drive a whole of governments approach and ensure its outcomes framework measures outcomes for Autistic Australians.

#### Recommendation

Develop the Roadmap (and National Autism Strategy) as a whole of governments initiative, and/or link to Australia's Disability Strategy to drive service integration, national consistency and collaboration, and comprehensive accountability measures.

## 2. Specify targeted actions for priority cohorts

We welcome recognition, in the Guiding Principles, of priority cohorts in need of targeted interventions and supports. We agree priority cohorts include Autistic people with complex and high communication and/or behaviour support needs, intersectional cohorts, people living in residential and institutional settings, and people living in rural and remote areas. However, we are concerned that the Focus Areas and Proposed Actions do little to directly address the specific needs of these cohorts. While some targeted actions are identified, they lack detail or are quite general in nature and need to be expanded upon.

To ensure that the Guiding Principles are truly reflected in the Focus Areas and Proposed Actions, and the needs of these cohorts are being addressed in a targeted way, we recommend that each of the ‘Possible actions for Focus Areas’ sections include a sub-section identifying possible targeted actions to specifically address the needs of each of these cohorts,

For example, further actions may include:

- Focus Area B: specific actions related to the proposed Autism Affirming Framework to ensure it includes a focus on priority cohorts and drives capacity building for healthcare professionals working with these cohorts, particularly to improve competencies in communication and behavioural support, and in safe interventions and strategies to avoid the use of restrictive practices.
- Focus Area C: specific actions to address the need for additional service co-ordination and integration for these priority cohorts, including an action to ensure navigators/liaison officers are well trained in the needs of these cohorts
- Focus Area D: specific actions to ensure autism education and training for health and mental health professionals focusses on the needs of each of these cohorts. Health practitioners specialised in the needs of these cohorts are also required, with all health and mental health practitioners able to access these practitioners (i.e. via the hotline proposed in Focus Area D). Training and resources must be developed in co-design with these priority cohorts and their families/carers to ensure their success.

The specific actions needed for priority cohorts must be identified in co-design and targeted engagement with these cohorts. We understand the complexities of reaching some of these groups and the need to ensure people feel safe to share their stories. However, if the current timeframes are not allowing these relationships to be built and these cross sections reached, we would recommend that the timeframes for the Roadmap’s development be extended to ensure their crucial perspectives and experiences can be heard and inform the Roadmap’s development and implementation.

### **Recommendations:**

- Each of the ‘Possible actions for Focus Areas’ sections in the Roadmap include a sub-section identifying targeted actions that specifically address the needs of priority cohorts.
- Extend current consultation timeframes to ensure Autistic people (and families and carers) from priority cohorts can inform targeted actions and the Roadmap’s broader development.

### 3. Prioritise preventative health and health promotion.

We welcome the Roadmap's recognition that Autistic women are less likely to receive basic reproductive and sexual health care, such as cervical cancer screenings and gynaecology visits, compared with non-Autistic individuals. However, a wider focus on prevention and health promotion is needed to drive an understanding and address the barriers Autistic people face to accessing preventative healthcare and health promotion information.

The [Disability Royal Commission](#) recently highlighted that people with disability are less likely to access annual health examinations, preventive dental care, screenings (such as pap tests and mammogram) and vaccinations. It highlighted that accessible information and communications about prevention and health promotion are lacking, together with accessible ways to access some of these services. It also found that health professionals can lack the skills and expertise needed to support people with disability to access these services. The [Senate Select Committee on Autism's Inquiry into services, support and life outcomes for Autistic Australians](#) similarly heard evidence about failures to provide accessible preventative healthcare services to Autistic people, and the need to consider Autistic people's needs in preventative healthcare initiatives to address high rates of potentially avoidable morbidity and hospitalisations.

The Australian Government's [National Preventative Health Strategy \(2021-2030\)](#) highlights the health inequalities experienced by people with disability and the need for additional support for those who experience the greatest inequities to complement whole of population programs. The Strategy identifies people with disability as a priority population and its commitments include developing health and health care information with priority populations, that is tailored, culturally appropriate and accessible.

We recommend that the Roadmap link to the National Preventative Health Strategy and contain actions and measures to ensure preventative healthcare and health promotion initiatives and information are accessible for Autistic people, builds their individual capacities and improves their health outcomes. We also recommend that the first Guiding Principle be amended to state: Understand and promote the individualised and intersecting needs of autistic individuals in health and mental health services, and preventative health and health promotion programs, policy and initiatives.

Actions should include:

- Funding annual health and mental health checks for Autistic people, with post assessment support to navigate any health and allied health services required.
- Review of health promotion initiatives and information resources to ensure they are accessible for Autistic people, including for example, cancer screening information, anti-smoking messaging and health promotion. Their dissemination should also be reviewed to ensure they are reaching all Autistic people, including vulnerable and hard to reach groups.

The Roadmap should also play a key role in driving further research and data collection to be better understand the experiences, outcomes and needs of Autistic people in this space.

## Recommendations.

- Link the Roadmap and National Preventative Health Strategy.
- In the Guiding Principles, highlight the importance of understanding and promoting the needs of Autistic individuals in preventive healthcare and health promotion programs, policies and initiatives.
- Specify actions to fund annual health and mental health checks for Autistic people.
- Review health promotion initiatives and information resources to ensure they are accessible for Autistic people.

## 4. Comprehensive actions for suicide prevention.

We welcome the Roadmap's recognition, in its second Guiding Principle, that mental health and suicide prevention are integral to good health. We also welcome the Roadmap's recognition of the increased rates of suicide, and suicidal thoughts and behaviours among Autistic people, compared to non-Autistic people, and the leading contributors to these higher rates, including commonly co-occurring mental health conditions, bullying, social isolation and self-harm behaviours, such as in the context of repetitive behaviours.

To further inform the Roadmap's development, we are pleased to highlight recently published global [research](#) (2024), and an evidence and lived experience informed [Policy Brief](#) (2024) by the Olga Tennison Autism Research Centre (OTARC), which illustrate that:

- Autistic people have a threefold to fivefold increased risk of death by suicide, compared to non-Autistic people.
- Autistic people without intellectual disability are more than five times more likely to die by suicide, compared to non-Autistic people.
- The risk of death by suicide for Autistic females relative to non-Autistic females is significantly larger than the risk for Autistic males relative to non-Autistic males.
- Among Autistic children, the average age of first suicide attempt is 12 years of age.
- Autistic people are at significantly increased risk of suicidal thoughts and behaviour, with 81% experiencing suicidal ideation.
- Autistic people are likely underrepresented in suicide data given the large numbers of Autistic people that remain undiagnosed.
- Autistic people experience heightened and unique factors that increase the risk of suicide, as well as unique barriers to accessing suicide prevention supports and services.
- Almost 2% of all suicide deaths globally in 2021 could have been avoided if the risk for death by suicide was not elevated for Autistic people.
- Globally in 2021, there was more fatal health burden due to suicide mortality among Autistic people than for cocaine use disorders, rabies, or testicular cancer among the total population.

We welcome the draft Roadmap's possible actions related to suicide prevention, including that: existing literacy resources for Autistic people and their families and carers be reviewed; suicide prevention be a priority area for future research; suicide prevention practice guidelines be incorporated into the proposed Autism Affirming Framework; the National Safety and Quality Health Services Standards address suicide prevention for Autistic people; primary health communities be strengthened to better connect and support health and mainstream sector professionals to address suicide prevention; and that ways of supporting Autism organisations to assist Autist people, and their families and carers, to engage with mental health, suicide prevention and connected service systems be explored.

To ensure suicide is comprehensively addressed in the Roadmap, we would encourage you to carefully review the barriers to suicide identified in the OTARC Policy Brief (2024) and ensure these are all addressed. Further barriers that are identified include general healthcare barriers (including across mental health services and suicide specific supports and services), economic barriers, location distance and travel, sensory sensitivity, communication barriers and provider barriers. It also highlights that these barriers are compounded by systemic factors including the complexity of systems (such as the NDIS) and scant availability of specialist autism-informed care.

We would also highlight the International Society for Autism Research (INSAR) Policy Brief titled [Autism Community Priorities for Suicide Prevention \(2021\)](#), which identifies further comprehensive actions to effectively identify, treat and support Autistic people at risk of suicide. In particular, that further actions should include adapting available treatments for suicidal thoughts and behaviours in partnership with autistic people and improving screening for suicide risk by health and mental health professionals.

Public consultation is currently underway on the National Suicide Prevention Office's advice to government on the National Suicide Prevention Strategy. In a submission to this consultation, we will be advocating for the advice to be adopted in full (constituting the Strategy) and for the Strategy to:

- Identify Autistic people as a priority cohort, as per recent steps taken in the UK's 2023 Suicide Prevention in England: 5-year cross-sector strategy, to identify Autistic people as a priority group for suicide prevention.
- Drive a whole of governments approach to autism and suicide prevention, with an autism lens applied to all national, state and territory policy and program development.
- Link to the Autism and Health Roadmap to ensure the Roadmap is not siloed from broader, whole of governments, suicide prevention policy, and ensure that the outcomes of the Strategy and Roadmap are robustly and comprehensively measured for Autistic people.

To enable the comprehensive measurement of outcomes, data collection must also be strengthened to better understand suicidal behaviour and deaths by suicide among Autistic people in Australia, including among priority cohorts. We would recommend that the Roadmap link to, or identify the [National Suicide and Self Harm Monitoring System](#) as an existing data set where identifiers could be strengthened to include autism identifiers.

**Recommendations:**

Ensure the Roadmap comprehensively addresses suicide prevention for Autistic people, and links to the National Suicide Prevention Strategy and National Suicide and Self Harm Monitoring System.





## 5. Specify actions to prevent, identify and treat co-occurring eating disorders.

We welcome the Roadmap's general recognition that eating disorders commonly co-occur with autism, however we are concerned that the Roadmap contains no specific actions to address eating disorders.

There is [evidence](#) that up to 30% of patients with anorexia are Autistic or display high levels of Autistic traits. Emerging research suggests that there is also a strong correlation between Avoidant and Restrictive Food Intake Disorder (ARFID) and autism, and in turn harmful nutrition deficiencies. For example, a [2019 study](#) found that atypical eating behaviours are significantly more common in Autistic children (70.4%) than in children with other disorders (13.1%) and neurotypical children (4.8%). For Autistic children who had atypical eating behaviours, the most common behaviour was limited food preferences (88%), followed by hypersensitivity to food textures (46%), other eating patterns, most often eating only one brand of food (27%), pocketing food without swallowing (19%), and pica (12%).

While every individual will have differing support needs, mainstream approaches to treating eating disorders such as anorexia and ARFID are often not appropriate for Autistic people and targeted, individualised, disability specific and neuroaffirming approaches are needed. Health practitioners do not have a consistent understanding of this and the utilisation of mainstream approaches for Autistic patients can often be ineffective or at worst, lead to harm. For more information regarding the relationship between autism and eating disorders, and treatment needs please see Eating Disorders Victoria's information webpage on [Eating Disorders and Autism](#). The high level of community and clinical interest in accessible and neuroaffirming, evidence informed approaches, is also highlighted in this recent [ABC News article](#).

Responsibilities for supporting Autistic people with eating disorders have been unclear for some time. We understand from our community engagement that eating disorder treatment providers often urge Autistic patients to access disability specific care, while disability service providers can in turn shift responsibility back to eating disorder or mental health service providers. As part of the latest suite of NDIS reforms, eating disorder services were identified as a support that is not a NDIS support in the draft list of NDIS Supports. This creates a further lack of clarity and we have [recommended](#) that this exclusion be reviewed to ensure targeted disability specific services can be accessed via the NDIS where appropriate.

As stated in the Roadmap, Autism CRC has recommended the development of targeted information and resources that address autism and eating disorders. We would also recommend actions for:

- Better approaches to screening for eating disorders among Autistic children, and screening for autism among patients presenting with eating disorders.
- Clearer and better co-ordinated care pathways and clarity regarding service system responsibilities.
- Improved understanding of eating disorders and autism across the healthcare community, including emergency departments.
- Consideration of how early intervention services, schools and community services may better identify and support Autistic children and teens with eating disorders.
- Equitable access to service providers trained in the support needs of Autistic people, including access to funding and a reduction in wait times for services.

- Investment in research and the development of tailored treatment approaches that are respectful, safe, accessible and appropriate for Autistic people.
- Funding for facilitated peer support networks.

Finally, we would recommend that the Roadmap specifically highlight the relationship between autism and pica (mouthing and/or eating non-food items), and autism and swallowing difficulties. Pica is experienced by [an estimated 12%](#) of Autistic people and is [most commonly experienced](#) by Autistic people (with the highest prevalence among Autistic people with a co-occurring intellectual disability), and an estimated 19% of Autistic people are at higher risk of pocketing their food without swallowing. Pica can relate to sensory or behaviour support needs or be a symptom of nutritional deficiency. It can cause a range of [health problems](#), including constipation, blockages in the digestive tract, poisoning and parasitic infection. [Injury and poisoning](#) are among the most common causes of death for Autistic people.

We recommend that the importance of prevention or management of pica and swallowing difficulties be included in the guiding principles as integral to good health and that specific actions be included to improve understandings of, and treatments for these conditions.

**Recommendation.**

- Specific actions to prevent, identify and treat eating disorders that commonly co-occur with autism, including anorexia, ARFID and pica, and drive clarity regarding service system responsibilities.

## 6. Specify actions to prevent, identify and treat co-occurring alcohol and drug use disorders

The Roadmap does not address autism and alcohol or drug use disorders. There is emerging [evidence](#) that Autistic people may be at a higher risk of drug and alcohol misuse than the general population, but under-represented within drug and alcohol support services. The evidence shows that treatment outcomes may be less favourable for Autistic patients than other groups, with likely barriers including a lack of autism-specific training and a lack of reasonable adjustments or adaptation of therapy to the needs of Autistic patients. Co-designed guidance is needed on how to best deliver alcohol and drug related therapy and supports to Autistic people, as well as co-designed training for practitioners.

**Recommendation.**

- In the Guiding Principles, highlight the service needs of Autistic people with alcohol and drug use disorders.
- Specify actions to co-design training and guidance for health practitioners on preventing, identifying, treating alcohol and drug use disorders among Autistic people, and drive further research into understanding and addressing alcohol and drug use disorders among this cohort.

## 7. Improve awareness of specialist services options.

In Focus Area A, we welcome the priority action to consider how to improve access to, and the affordability of specialist services. Greater availability of community-based specialist services is urgently needed, particularly in rural and remote areas. Better awareness and understanding of existing specialist service options is also needed. Through our Autism Connect helpline and community engagement we have regularly heard from Autistic people and their families who are unaware of specialist services that may be available to them or how they may access these services. Healthcare providers can lack knowledge of these services, and advice on how to access them can be inconsistent.

Accordingly, we recommend that Focus Area A include an action to review and develop information resources for health professionals, Autistic people and their families/carers about specialist service options. These resources should be developed in co-design with relevant stakeholders, including Autistic people, their families and carers and sector organisations. They should include easy read information about specialist service options and referral pathways, and information to support the decision making of individuals and/or where appropriate, their families and carers.

### **Recommendations.**

In Focus Area A, include actions to review and co-design information resources for health professionals, Autistic people and their families and cares about specialist service options.