

27 September 2024

Autism Health Roadmap Consultation Team
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Submitted via survey: <https://consultations.health.gov.au/primary-care-mental-health-division/autism-health-roadmap/>

APS Survey Responses to the Consultation about the Draft National Roadmap to Improve the Health and Mental Health of Autistic People (the Autism Health Roadmap)

Agreement to responding to the survey
<p>1. The Department of Health and Aged Care would like to publish parts of your response to this survey. Which parts of your response can we use? (Required)</p> <ul style="list-style-type: none"> • All of my response (anything I say and information I provide about myself in this survey) • De-identified parts of my responses • Do not publish my response
<p>2. Which of the following best describe you? (Please select all that apply.)</p> <ul style="list-style-type: none"> • I am an Autistic person / I think I might be Autistic • I am an unpaid carer, family member or friend of an Autistic person or people • I am a medical professional • I am an allied health professional • I am a researcher • I am a disability support worker, educator or support coordinator • I work in a not for profit organisation, advocacy organisation or peak body • I work in federal, state/territory or local government
<p>3. Are you responding for an organisation or representing a group? If yes, please provide the group or organisation's name in the box below.</p> <p>Australian Psychological Society (APS)</p> <p>The APS is the leading professional association for psychologists in Australia. Psychologists work in diverse ways and contexts to unlock the full potential of individuals, organisations and their communities through the application of psychological science and knowledge. At the APS, we are dedicated to advancing the scientific discipline, ethical practice and application of psychology within our society. Our work is informed by a human rights approach and aligned with the United Nations' Sustainable Development Goals (SDGs). We advocate for a fair, inclusive and environmentally sustainable world, recognising the evidence that national and global prosperity now and in the future hinges on prioritising the health and wellbeing of people and the planet.</p>
Section 1 Guiding Principles
<p>1. Guiding Principle: Understand and promote the individualised and intersecting needs of Autistic individuals in health and mental health services</p> <p><i>Aspects of a person's identity can overlap to create unique experiences of discrimination, disadvantage, and inequality. For one person, autism could be one facet of an intersectional experience with a variety of other aspects of their identity that might also lend to further discrimination or complexity. For example, an Autistic person who may also be gender diverse, or a person of colour, a victim of gender-based violence or have a co-existing physical disability, will likely experience compounded disadvantage. The Autistic person's interactions with the world will need to be relational and intersectional rather than compartmentalised or siloed transactions on isolated aspects of their identity.</i></p> <p><i>Because of this, every aspect of improving the health and mental health of Autistic people needs to be founded within this recognition. All priorities put forward within this Roadmap recognise that there is no one size fits all approaches that will work. Rather, people's experiences of health and mental health services are influenced by their intersectional identities. As articulated throughout the Autism Health Roadmap, health and mental health services should make efforts to consider these experiences when providing services.</i></p>

How important is this principle to the Roadmap? (Select one option)

- Not important
- Important
- **Very important**
- Unsure

2. Guiding Principle: Recognise mental health and suicide prevention as integral to good health

Mental health is a key aspect of general health and wellbeing. Autistic people experience poorer mental health, including higher rates of co-occurring mental health conditions than non-Autistic people. They are also more at risk of experiences that can contribute to poor mental health, including bullying and social isolation. Noting that suicidality is not necessarily linked to a mental health condition, but often considered to be related to mental health, we note that Autistic people are also at greater risk of suicide. Additionally, Autistic people are at a higher risk of self-harm behaviours, such as in the context of repetitive behaviours. Autistic people are also significantly more likely to die by self-harm.

These inequities are perpetuated when mental health is considered to be separate to, or separately from, physical health. To acknowledge that mental health is integral to, not separate from, a person's overall health, the Roadmap considers outcomes and actions that relate to mental health throughout, not separately from other areas of health.

How important is this principle to the Roadmap? (Select one option)

- Not important
- Important
- **Very important**
- Unsure

3. Guiding Principle: Ensure partnership and inclusion by involving Autistic individuals, their families and carers in decisions that affect them

Co-design is an investigative and creative process that brings together people who are impacted by the product, service, or resource (also known as 'outputs') and people with knowledge and technical skills to jointly create that output. Co-design aims to empower and put people with lived experience at the centre of the design process, recognising that people with lived experience are the people who know best. This is particularly important when the people who will be the recipients, or users, of a service may think and perceive the world differently to those who would otherwise lead it.

The Autism Health Roadmap has been co-designed, co-reviewed and will be co-delivered with Autistic people, their families and carers and support networks. It is critical that any initiative stemming from the outcomes and actions outlined in the Autism Health Roadmap should embed the fundamental principle of engaging with Autistic people, their families and carers in the planning, design, governance, implementation and evaluation of the Roadmap.

How important is this principle to the Roadmap? (Select one option)

- Not important
- Important
- **Very important**
- Unsure

4. Guiding Principle: Services for Autistic people, their families and carers should be universally accessible

Universal design involves ensuring that policies, programs, and services are accessible to as many people as possible inclusive of age, ability, gender identity, culture, language, and any other social characteristics.

For Autistic people, this would mean that services are easier to access. For example, information could be provided in a greater range of ways or services could have more flexible appointment times.

How important is this principle to the Roadmap? (Select one option)

- Not important
- Important
- **Very important**
- Unsure

5. Guiding Principle: Uphold human rights, self-determination, and autonomy of Autistic people

Autistic people have the right to be respected and safe from all forms of discrimination, vilification, violence, and abuse throughout their lives. This is in line with the United Nations Convention on the Rights of Persons with Disabilities (UNCPRD), to which Australia is a signatory. Specific articles which are key to this include: Article 25 (right to the highest attainable standard of health) and Article 3 (freedom to make choices).

There should be freedom of choice, control and support for Autistic people to make their own individual decisions across the lifespan, about all aspects of health and health care.

How important is this principle to the Roadmap? (Select one option)

- Not important
- Important
- **Very important**
- Unsure

6. Guiding Principle: Acknowledge and cater to the needs of specific priority groups of Autistic people

As a result of many historical and cultural factors, particular groups of people in our society experience higher rates of disadvantage, greater barriers accessing services or other forms of inequities than others. Groups which are focused on in the Autism Health Roadmap are as follows:

- *people with high or complex disability needs, including:*
- *complex communication needs*
- *complex behaviour support needs*
- *people in residential settings*
- *people in institutional settings*
- *people with intellectual disability*
- *First Nations peoples*
- *culturally and linguistically diverse people*
- *LGBTIQ+ people*
- *women and girls*
- *people who live in rural and remote areas*
- *people who are from low socio-economic backgrounds*

Any efforts to improve the health and mental health of Autistic people should consider specific ways to target and improve the lives of these groups of people. Where evidence demonstrates the benefit of specific interventions for different priority groups, those interventions should be supported.

How important is this principle to the Roadmap? (Select one option)

- Not important
- Important
- **Very important**
- Unsure

7. Do you have any suggestions to improve the Guiding Principles?

For this question, we want to know:

- Are there other Guiding Principles that should be included in the Autism Health Roadmap? If so, what are they?
- Should any of the proposed Guiding Principles be changed in the Autism Health Roadmap and why? If so, how should they be changed?

- While the Roadmap mentions the need for services across the lifespan, a specific guiding principle on a **lifespan approach** could ensure that health and mental health services consider the evolving needs of Autistic people at different life stages—from childhood, through adolescence and adulthood, to later life. This principle would promote the creation of services that are age-appropriate and address the changing needs of Autistic people as they age. Alternatively, a lifespan approach could be incorporated as part of Guiding Principle 1, for example, *Understand and promote the individualised, intersecting, and evolving needs of Autistic individuals in health and mental health services across their lifespan.*
- Given the higher prevalence of adverse experiences, including bullying and discrimination, among Autistic people (as acknowledged throughout the document), it might be beneficial to include within the Roadmap a specific guiding principle on the provision of **trauma-informed care**. This principle would ensure that all health and mental health services are sensitive to the potential for trauma and provide support in a way that does not retraumatise individuals. Alternatively, trauma-informed care could be incorporated as part of Guiding Principle 5, for example, *Services for Autistic people, their families and carers should be universally accessible and delivered within a trauma informed approach.*
- The APS highly commends the specific guiding principle that recognises cohorts of Autistic people who have been typically under-served and at higher risk of adverse health and mental health outcomes. We especially commend the inclusion of women and girls and LGBTIQ+ cohorts. We recommend the principle statement be developed further **to identify key principles of practice with regards to these cohorts, such as respect and cultural safety**. For example, Guiding Principle 6 could be extended as follows: *Acknowledge and cater to the specific needs of priority groups of Autistic people by ensuring services are culturally safe and respect the unique experiences of diverse populations and other marginalised groups.*
- We note there is some discussion of the following cohorts in parts of the Roadmap, but we request consideration be given to explicitly identifying them as priority populations:
 - It is essential to explicitly recognise **Autistic infants, toddlers and their family, carers and kin** as a priority population for improving health and mental health of autistic people. Early childhood, as emphasised in key national strategies (e.g., the national Early Years Strategy 2024-2034 and the National Children's Mental Health and Wellbeing Strategy) is a critical period for shaping lifelong health and wellbeing outcomes. Early, targeted health and mental health interventions are key to promoting long-term positive outcomes, reducing developmental inequities and fostering meaningful social inclusion from the very start of life.

- **Autistic parents** are a significant but overlooked group in current support structures. Undiagnosed parents, particularly mothers, face heightened challenges during the perinatal period and are overrepresented in perinatal mental health services. Additionally, parents with Autistic children who receive NDIS funding are unable to allocate this funding for their own parenting support, exacerbating their already complex caregiving responsibilities. Existing parenting programs are often inadequate for Autistic people. These programs do not accommodate or screen for autism among parents nor do they offer tailored support to address the unique needs of Autistic individuals in their parenting role. This gap underscores the urgent need to focus on Autistic parents and mothers and ensure provisions for family-focused supports that consider the entire familial context, rather than solely focusing on the individual.
- **Homeless Autistic people** - there is research identifying Autistic individuals as being at higher risk of homelessness.
- While some **older Autistic people** reside in residential care settings as per the priority populations list, we also call for all older Autistic adults to be an identified priority population for improving health and mental health services. As they age, Autistic individuals face unique challenges, including adapting to changing environments, managing co-occurring health conditions and navigating a system not tailored to their neurodiverse needs. Without targeted interventions, older Autistic adults are at increased risk of social isolation, misdiagnosis and inadequate care. Recognising their specific needs is essential to ensure they receive respectful, individualised and appropriate support that promotes their quality of life and dignity in later years, not only for those in residential aged care.

Section 2: Feedback on possible actions

Focus Area A

Improving support for Autistic people, their families and carers, in health and mental health services.

The intended outcomes for this Focus Area are summarised below.

- *Facilities accommodate sensory, communication and accessibility needs*
- *Information and resources about services are accessible*
- *Autistic people know and understand information, health rights and informed consent; actively supported to participate as equal partners*
- *Autistic people's interoceptive differences are understood, supported, and accommodated*
- *Health practitioners skilled and proactive in upholding Autistic people's rights*
- *Autistic people supported to make informed decisions*
- *Financial and administrative barriers to accessing services reduced*

This section asks you about specific possible Actions for Focus Area A.

The below actions are intended to be carried out across a 10-year workplan.

1. How important is the following action to the Autism Health Roadmap?

Review, collate and investigate the best examples of health and mental health literacy resources for Autistic people, their families, and carers in partnership with Autistic and autism community members. These resources would provide examples for the further development of health literacy resources.

- Not important
- Important
- **Very important**
- Unsure

2. How important is the following action to the Autism Health Roadmap?

Review existing, or if needed develop and promote, tools for best practice models of care for supporting autonomy, facilitating support for decision-making, obtaining informed consent for treatment, and ensuring adequate and ethical safeguards for those that lack capacity to provide informed consent. These models should also consider the role of parents, carers, and guardians.

- Not important
- Important
- **Very important**
- Unsure

3. How important is the following action to the Autism Health Roadmap?

Regularly review existing Australian Government health and mental health information and resources for consumers and health practitioners, to ensure Autistic people's needs are explicitly addressed.

- Not important
- Important
- **Very important**
- Unsure

4. How important is the following action to the Autism Health Roadmap?

Develop information in areas identified as key gaps in the review of health literacy resources for Autistic people. Key topics could include:

- when you might need to see a professional
 - how different kinds of professionals can help
 - how to navigate services, including making appointments
 - the traits/characteristics and varied presentations of autism
 - pain expression, interoception, emotions and alexithymia.
-
- Not important
 - Important
 - **Very important**
 - Unsure

5. How important is the following action to the Autism Health Roadmap?

Establish requirements for autism friendly spaces and other autism adjustments in the Australasian Health Facility Guidelines and related building and accessibility standards. Updates to these guidelines should include consultation with Autistic people to ensure these revisions are appropriate for the needs of Autistic people, families and carers.

- Not important
- Important
- **Very important**
- Unsure

6. How important is the following action to the Autism Health Roadmap?

Develop resources for health and mental health professionals and service staff to improve their understanding and competency regarding Autistic traits, interoception, distress and pain expression in autism in partnership with Autistic people, autism community members and health practitioners. Ensure that these resources refer to or build on existing tools or instruments that support practice.

- Not important
- Important
- **Very important**
- Unsure

7. How important is the following action to the Autism Health Roadmap?

As a priority action, consider how to improve access to and affordability of primary care services, including general practice, to address the health and mental health needs of Autistic people. This could include considering:

- different funding models to allow for more timely and affordable diagnosis pathways for Autistic people of all ages
- exploring innovative models of diagnosis, treatment and care coordination in primary care and community-based specialist services.
- longer consultations to accommodate different cognitive processing and communication needs, and complex mental health needs
- otherwise increasing affordability and ways that health professionals can provide additional health and mental health supports to Autistic people, including referring Autistic people to free publicly available services if appropriate and/or peer support services.

- Not important
- Important
- **Very important**
- Unsure

8. How important is the following action to the Autism Health Roadmap?

The Australian Commission on Safety and Quality in Health Care could:

- develop and promote guidance for health service organisations and clinicians in line with the Autism Affirming Framework such as fact sheets, evidence briefs and webinars
- develop information for priority groups, including Autistic people, to raise awareness of the Australian Charter of Health Care Rights including development of an Easy Read version
- consider Autistic people's needs in ongoing work related to health literacy (see Focus Area B).

- Not important
- Important
- **Very important**
- Unsure

9. Do you have anything you want to say about the actions for Focus Area A?

For this question, we want to know:

- Are there other actions that should be included in the Autism Health Roadmap? If so, what are they?
- Should any of the proposed actions be changed in the Autism Health Roadmap and why? If so, how should they be changed?

- The review and development of various resources and guidelines as described in the current actions for this focus area are very important, but these will only be impactful if they are easily accessible to Autistic people, their families, carers and kin as well as health professionals. Thus, an additional essential action is the **funding of a resource hub/gateway** to create an easily accessible, centralised digital site that provides comprehensive, up-to-date resources on autism-specific health and mental health services, available supports, and guidance on navigating the healthcare system. This hub should include information in multiple formats, including Easy Read, videos, and alternative communication methods. A professional resources section hosted on the same platform can help to ensure transparency of information between autistic people and health professionals.
- We recommend consideration to be given to **extending and adapting as necessary the annual medical check-ups for people with intellectual disability to Autistic people (Comprehensive Health Assessment Program (CHAP))** including a screen for mental health needs. This would necessarily involve a review of the evidence to better understand the value of such initiatives for Autistic people.
- Childcare and educational settings are critical environments for Autistic children, youth, and their families, carers and kin during the first two decades of life. We call for **integrating more specialised support within schools and early childhood education settings to address the holistic health, wellbeing, and developmental needs of Autistic children, beyond learning**. Psychologists, and especially educational and developmental psychologists, are experts in mental health, development, and learning, and play a vital role in these settings but are currently underfunded. Increasing the ratio to at least 1 psychologist per 500 students, as recommended by the Productivity Commission, would ensure better support for Autistic children and their families, improve access to health and mental health services, and help mitigate the financial barriers to care. For further details, refer to the APS Psychologists in Schools Position Statement for recommendations on growing the psychology workforce in educational settings <https://psychology.org.au/getmedia/3478fa00-0a90-43ff-8d90-99a42ea53981/22aps-ps-psysch-p1.pdf?target=...>

Section 2: Focus Area B

Improving the quality, safety and availability of Autism affirming health and mental health care across their lifespan

The intended outcomes for this Focus Area are summarised below.

- Health and mental health services are guided by an Autism Affirming Framework – a guide and list of competencies for working with Autistic people
- Health and mental health services work together as one service to make it easier for Autistic people
- All Autistic people accommodated in health and mental health services
- All restrictive practices are reduced, and harmful restrictive practices are eliminated
- Health practitioners are able to support all Autistic people to make decisions
- Autistic people are protected against chemical restraint (using medications to control unwanted behaviour)
- Diagnostic overshadowing (treating only autism and not other conditions you might have) is reduced.

This section asks you about specific possible Actions for Focus Area B.

The below actions are intended to be carried out across a 10-year workplan.

1. How important is the following action to the Autism Health Roadmap?

Co-design and develop a national theory and practice framework for Autism Affirming care (Autism Affirming Framework). This could include individual and organisational definitions and descriptors of autism practice approaches (trauma informed care) and be mapped to existing health, mental health and suicide prevention practice guidelines and service models.

- Not important
- Important
- **Very important**
- Unsure

2. How important is the following action to the Autism Health Roadmap?

Review existing health and mental health initiatives that include Autistic people as a focus cohort and align them with the definitions and practice descriptions of an Autism Affirming Framework.

- Not important
- Important
- **Very important**
- Unsure

3. How important is the following action to the Autism Health Roadmap?

Align efforts to support general practitioners with current reforms in Primary Health Care, particularly actions around integrated person-centred care. Promote understanding of autism within existing sector reform efforts, including exploring further provisions that enable general practitioners to spend more time with Autistic patients and consideration of the communication needs and diverse abilities of Autistic people, including those with co-occurring conditions and complex disability support needs.

- Not important
- [Important](#)
- Very important
- Unsure

4. How important is the following action to the Autism Health Roadmap?

Promote best practice care of Autistic people within existing sector reform efforts based on an Autism Affirming Framework. This could include further provisions that enable health practitioners to spend more time with Autistic patients. Further, that there is more consideration of the communication needs and abilities of Autistic people, including those with co-occurring conditions and complex or high disability support needs.

- Not important
- Important
- [Very important](#)
- Unsure

5. How important is the following action to the Autism Health Roadmap?

Pilot and promote best practice models of Autism Affirming care, as defined by an Autism Affirming Framework. Ensure that the specialised needs of the priority populations are considered in selection of the pilots.

- Not important
- Important
- [Very important](#)
- Unsure

6. How important is the following action to the Autism Health Roadmap?

As part of an upcoming review of the National Safety and Quality Health Services (NSQHS) Standards, consider how they may be able to be more applicable to autism and alignment to an Autism Affirming Framework. This should include self-harm, suicide risk mitigation, and the reduction of all and elimination of harmful restrictive practices.

- Not important
- Important
- [Very important](#)
- Unsure

7. How important is the following action to the Autism Health Roadmap?

Co-develop practice guidance and education material on the use of psychotropic medicines for Autistic people and Autistic experiences of chemical restraint, with reference to:

- an Autism Affirming Framework
 - the Psychotropic Medicines in Cognitive Disability or Impairment Clinical Care Standard
 - existing evidence and practice guidance on the use of medicines to address behaviours with Autistic peoples, including systematic reviews of pharmacological interventions, alternatives to prescribing medicines, and deprescribing practices.
- Not important
 - Important
 - [Very important](#)
 - Unsure

8. How important is the following action to the Autism Health Roadmap?

Promote pathways for Autistic people, their families and carers to raise complaints with health services and practitioners, and to escalate complaints where required.

- Not important
- Important
- [Very important](#)
- Unsure

<p>9. How important is the following action to the Autism Health Roadmap?</p> <p>Consider evidence from the Autism Affirming Framework as part of the upcoming review of the National Safety and Quality Health Services (NSQHS) Standards.</p> <ul style="list-style-type: none"> • Not important • Important • Very important • Unsure
<p>10. How important is the following action to the Autism Health Roadmap?</p> <p>Review the safety and quality aspects of health service practice guidance and education material on the use of psychotropic medicines to consider the needs and experiences of Autistic people.</p> <ul style="list-style-type: none"> • Not important • Important • Very important • Unsure
<p>11. Do you have anything you want to say about the actions for Focus Area B?</p> <p>For this question, we want to know:</p> <ul style="list-style-type: none"> • Are there other actions that should be included in the Autism Health Roadmap? If so, what are they? • Should any of the proposed actions be changed in the Autism Health Roadmap and why? If so, how should they be changed?
<ul style="list-style-type: none"> • We call for more support for psychologists to provide evidence-based mental health care to older adults as part of Commonwealth funded aged care services, both support at home and residential aged care. This will help to eliminate the inappropriate use of restrictive practices such as psychotropic medications for all older Australians, including older Autistic people. More details are available in the APS Psychologists in Residential Aged Care Position Statement https://psychology.org.au/about-us/position-statements/psychologists-in-residential-aged-care
<p>Section 2: Focus Area C</p> <p>Building better connections between health, mental health and other service sectors, including the NDIS</p> <p>The intended outcomes for this Focus Area are summarised below.</p> <ul style="list-style-type: none"> • Autistic people are supported during transitions between different settings and life stages • Improved integrated health and mental health care • Timely and specialised health and mental health service linkage <p>This section ask you about specific possible Actions for Focus Area C.</p> <p>The below actions are intended to be carried out across a 10-year workplan.</p>
<p>1. How important is the following action to the Autism Health Roadmap?</p> <p>Develop and publicise an 'autism passport' which is an accessible and practical tool for Autistic people to share information with health services. The passport should contain information on an individual's sensory, cognitive, communication, co-occurring conditions, and treatment preferences. Opportunities for digital integration could also be explored.</p> <ul style="list-style-type: none"> • Not important • Important • Very important • Unsure
<p>2. How important is the following action to the Autism Health Roadmap?</p> <p>Establish or build upon existing primary health communities of practice to connect and support health and mainstream sector professionals to improve regional coordination and responsiveness to health, mental health and mainstream support needs of Autistic people.</p> <ul style="list-style-type: none"> • Not important • Important • Very important • Unsure
<p>3. How important is the following action to the Autism Health Roadmap?</p> <p>Consider potential models to for Autistic and autism-proficient service navigators/liaison officers in health and mental health services. Consider whether disability health navigators (recommended in the NDIS Review and Disability Royal Commission) could be equipped to play this role.</p> <ul style="list-style-type: none"> • Not important • Important • Very important • Unsure

<p>4. How important is the following action to the Autism Health Roadmap?</p> <p>Work in partnership with states and territories on specialised multi-disciplinary health and mental health care service options, either improving existing services or establishing new services. These centres could provide comprehensive, physical, and mental health care planning and services, including telehealth, tailored to Autistic people and capable of working with people with highly complex conditions.</p> <ul style="list-style-type: none"> • Not important • Important • Very important • Unsure
<p>5. How important is the following action to the Autism Health Roadmap?</p> <p>Consider ways to support Autism organisations to ensure that they can assist Autistic people, their families and carers with engaging health, mental health, suicide prevention and connected service systems.</p> <ul style="list-style-type: none"> • Not important • Important • Very important • Unsure
<p>6. Do you have anything you want to say about the actions for Focus Area C?</p> <p>For this question, we want to know:</p> <ul style="list-style-type: none"> • Are there other actions that should be included in the Autism Health Roadmap? If so, what are they? • Should any of the proposed actions be changed in the Autism Health Roadmap and why? If so, how should they be changed?
<p>No additional comments</p>
<p>Section 2: Focus Area D</p> <p>Improving autism education and training for health and disability professionals</p> <p>The intended outcomes for this Focus Area are summarised below.</p> <ul style="list-style-type: none"> • Resources, created with Autistic people, are available for all health practitioners • All health professionals are able to communicate and engage with Autistic people in ways that lead to Autistic people's health and mental health needs being better met • There is a program of professional development to improve the capability of health workers • Autistic people are supported to train as health and mental health workers <p>This section asks you about specific possible Actions for Focus Area D.</p> <p>The below actions are intended to be carried out across a 10-year workplan.</p>
<p>1. How important is the following action to the Autism Health Roadmap?</p> <p>Enhance existing resources and/or establish additional resources or services, for health and mental health practitioners in primary care supporting Autistic patients who need care beyond the practitioner's direct expertise. Examples might include:</p> <ul style="list-style-type: none"> • an extension of Health Pathways • hotline to a specialised health practitioner • Primary Health Network resources provided to local practitioners <ul style="list-style-type: none"> • Not important • Important • Very important • Unsure
<p>2. How important is the following action to the Autism Health Roadmap?</p> <p>The Department of Health and Aged Care to improve how other Government areas work with Autistic people and how they can improve their health and mental health.</p> <ul style="list-style-type: none"> • Not important • Important • Very important • Unsure
<p>3. How important is the following action to the Autism Health Roadmap?</p> <p>Consider options for a competency-based national program of professional development to improve health and mental health workforce in the following areas (could be aligned with an Autism Affirming Framework):</p>

<ul style="list-style-type: none"> • autism, including diverse presentations, communication, interoception, alexithymia and pain expression • intersectionality and complexity • National Standards of care and how they apply to autism • relevant legislative frameworks, adjustments, and accommodations • informed consent and assent for all Autistic people, with a specific focus on people who do not have the capacity to give informed consent • supporting people with very high and complex disability needs • supporting Autistic people when they are in crisis situations • trauma-informed care. <ul style="list-style-type: none"> • Not important • Important • Very important • Unsure
<p>4. Do you have anything you want to say about the actions for Focus Area D?</p> <p>For this question, we want to know:</p> <ul style="list-style-type: none"> • Are there other actions that should be included in the Autism Health Roadmap? If so, what are they? • Should any of the proposed actions be changed in the Autism Health Roadmap and why? If so, how should they be changed?
<ul style="list-style-type: none"> • The APS very much welcomes the commitment in the Roadmap to “Improving autism education and training for health and disability professionals”. The APS is well placed to co-design such work as the peak professional association for psychologists and to work alongside Autistic people and other health professional bodies who play a key role in supporting the health and mental health and wellbeing of Autistic people. We would welcome the development of a national standard for training in assessment and diagnosis of autism, noting the APS would be well placed to collaborate in the development of such standards.
<p>Section 2: Focus Area E</p> <p>Research and data on health and mental health outcomes of Autistic people and their families and carers</p> <p>The intended outcomes for this Focus Area are summarised below.</p> <ul style="list-style-type: none"> • Services routinely collect data to identify Autistic people and report nationally • Services have access to evidence and research translation materials, communities of practice, research partnerships and insights specific to Autism populations • Research conducted in partnership with Autistic people, families, carers, autism community members; focused on priorities to reduce health inequities experienced <p>This section asks you about specific possible Actions for Focus Area E.</p> <p>The below actions are intended to be carried out across a 10-year workplan.</p>
<p>1. How important is the following action to the Autism Health Roadmap?</p> <p>Consider funding research which identifies strategies to improve Autistic people's overall health and healthcare. Priority areas and population groups may include:</p> <ul style="list-style-type: none"> • child and adolescent health and mental health • addresses diagnostic overshadowing • suicide prevention • intersections of autism health with intellectual and cognitive disabilities • women's and reproductive health <ul style="list-style-type: none"> • Not important • Important • Very important • Unsure
<p>2. How important is the following action to the Autism Health Roadmap?</p> <p>Conduct a set of systematic reviews to address current research and practice gaps, such as considerations relating to understanding of health, mental health and suicide prevention outcomes for Autistic people, including:</p> <ul style="list-style-type: none"> • existing health and mental health data • unmet health, mental health, and crisis response needs • referrals • mandatory reporting of adverse outcomes, and other relevant metrics. <ul style="list-style-type: none"> • Not important • Important • Very important • Unsure

<p>3. How important is the following action to the Autism Health Roadmap? Leverage existing and upcoming data and reporting reforms, where disability identifiers in data sets are being improved to develop a comprehensive and consistent set of autism identifiers. This would be required for an ongoing basis of national health and mental health data collections and reporting.</p> <ul style="list-style-type: none"> • Not important • Important • Very important • Unsure
<p>4. How important is the following action to the Autism Health Roadmap? Develop and establish national evidence-based standards in pain measurement for Autistic people. This should have applicability across diverse settings such as primary care, bedside care, ambulance transport and childbirth, plus across all ages, abilities and intersectional experiences.</p> <ul style="list-style-type: none"> • Not important • Important • Very important • Unsure
<p>5. How important is the following action to the Autism Health Roadmap? Review the current measurement tools and practice guidelines used to identify co-occurring health and mental health conditions for Autistic people. The review should identify options for further development of existing or new tools and guidelines that are appropriate for Autistic people. The options should be valid for Autistic people with co-existing conditions and for priority populations.</p> <ul style="list-style-type: none"> • Not important • Important • Very important • Unsure
<p>6. Do you have anything you want to say about the actions for Focus Area E? For this question, we want to know:</p> <ul style="list-style-type: none"> • Are there other actions that should be included in the Autism Health Roadmap? If so, what are they? • Should any of the proposed actions be changed in the Autism Health Roadmap and why? If so, how should they be changed?
<p>No additional comments.</p>
<p>Section 2: Focus Area F Arrangements for oversight, monitoring and implementation The intended outcomes for this Focus Area are summarised below.</p> <ul style="list-style-type: none"> • The work of the Autism Health Roadmap is guided by a group of stakeholders (including Autistic people) to improve health and mental health outcomes for Autistic people • There is access to information about the work of the Autism Health Roadmap • Work to improve health and mental health has set timeframes <p>This section asks you about specific possible Actions for Focus Area F. The below actions are intended to be carried out across a 10-year workplan.</p>
<p>1. How important is the following action to the Autism Health Roadmap? Establish a Governance Group to oversee and monitor work to improve the health and mental health of Autistic people. This should include Autistic and autism representatives, practitioners and their representative bodies, and government representatives.</p> <ul style="list-style-type: none"> • Not important • Important • Very important • Unsure
<p>2. How important is the following action to the Autism Health Roadmap? Report annually on implementation of the Roadmap and progress of work to improve the health and mental health of Autistic people.</p> <ul style="list-style-type: none"> • Not important • Important • Very important • Unsure

<p>3. How important is the following action to the Autism Health Roadmap?</p> <p>Consider development of an Outcomes, Monitoring and Evaluation Framework. Critical data gaps should be identified and addressed.</p> <ul style="list-style-type: none"> • Not important • Important • Very important • Unsure
<p>4. Do you have anything you want to say about the actions for Focus Area F?</p> <p>For this question, we want to know:</p> <ul style="list-style-type: none"> • Are there other actions that should be included in the Autism Health Roadmap? If so, what are they? • Should any of the proposed actions be changed in the Autism Health Roadmap and why? If so, how should they be changed?
<p>The success of this Roadmap will heavily rely on the strength, timeliness and implementation of governance and action, evaluation plans and the ongoing, deep and authentic involvement of Autistic people and the Autistic community. Effective governance is essential to ensure coordinated and responsive efforts across federal, state, territory and local government levels, while robust action plans are necessary to translate the guiding principles and actions into tangible outcomes. Additionally, rigorous evaluation mechanisms must be in place to assess progress, identify gaps and drive continuous improvement. Only through diligent execution and co-production with Autistic people, their supporters and health professionals can the Roadmap achieve its intended impact and deliver meaningful support to the Autistic community.</p>
<p>Section 3: Opportunities and Gaps</p>
<p>1. Are there any new ideas or improvements you'd like to see included in the Autism Health Roadmap?</p> <ul style="list-style-type: none"> • We are concerned about some 'soft' and ambiguous commitments throughout a Roadmap that will be implemented over a 10 year period, for example: "As a priority action, <u>consider how to improve access to and affordability</u> of primary care services . . ." "Consider <u>options</u> for a competency-based national program of professional development . . ." "Consider <u>funding</u> research . . ." Our members have advised that this language may undermine the Autistic community's trust in the Government to commit to the actions needed to deliver on the Roadmap outcomes. We recommend strengthening commitments like those identified above to better align with the achievement of meaningful outcomes over a 10 year span, enhance transparency and build trust among Autistic community members, their supporters and other Roadmap stakeholders. • More detailed and actionable strategies for suicide and self-harm prevention for Autistic people is warranted in the Roadmap. Autistic individuals are at higher risk of suicidality than the general population, but the current Roadmap provides limited guidance on how to address these challenges. Strengthening the Roadmap with targeted actions, such as early identification, tailored interventions and specialised support, will be essential in reducing these risks and improving mental health outcomes for Autistic people.
<p>2. Is there anything you think is missing from the Autism Health Roadmap?</p> <p>Thank you for the opportunity to provide feedback about the Roadmap. The APS, as a member of the working group, looks forward to continuing to support the Government in the finalisation of the Roadmap, and its ongoing implementation and evaluation in order to help all Autistic people across Australia live the lives they want and deserve.</p>
<p>Section 4: About you</p>
<p>1. What state or territory do you live in? (Please select one option.)</p> <ul style="list-style-type: none"> • Australian Capital Territory • New South Wales • Northern Territory • Queensland • South Australia • Tasmania • Victoria • Western Australia • I do not live in Australia • Prefer not to say
<p>2. Where do you live? (Please select one option.)</p> <ul style="list-style-type: none"> • In a city or metropolitan area • In a regional, rural or remote area • Prefer not to say
<p>3. What is your gender? (Please select one option.)</p> <ul style="list-style-type: none"> • Man or male • Woman or female • Transgender

<ul style="list-style-type: none"> • Non-binary • No gender • Prefer not to say
4. Do you identify as intersex? (Please select one option.) <ul style="list-style-type: none"> • Yes • No • Prefer not to answer
5. How old are you? (Please type your age in the text box.) NA
6. Do you identify as Aboriginal and/or Torres Strait Islander? (Please select one option.) <ul style="list-style-type: none"> • Yes- Aboriginal • Yes- Torres Strait Islander • Yes- Both Aboriginal and Torres Strait Islander • No • Prefer not to say
7. How do you describe your sexual orientation? (Please select one option.) <ul style="list-style-type: none"> • Heterosexual • Gay or lesbian • Bisexual • Asexual • Queer • Don't know • Prefer not to answer • I use a different term to describe my sexual orientation
8. Do you have any disabilities or health conditions? (Please select one option.) <ul style="list-style-type: none"> • Yes • No • Prefer not to say • I have the following disabilities or health conditions
9. Do you often use a language other than English at home? (Select one option.) <ul style="list-style-type: none"> • Yes • No • Prefer not to say
10. What other language/s do you speak at home? (Please select all that apply.) <ul style="list-style-type: none"> • Arabic • Cantonese/Mandarin • Greek • Hindi • Italian • Punjabi • Spanish • Tagalog • Vietnamese • Other (please specify) • Prefer not to say • I do not speak another language at home