

Research evidence and policy landscape mapping to inform the National Autism Strategy

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Cover artwork: Jasmin Pradha, *Spiral of diversity*, 2018 Autism CRC Digital Art Celebration entry.

“My image is made up of words that describe diversity, what it means and how important it is. The words all make a spiral shape across the page.”

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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.

Autism CRC was established in 2013 as the world's first national, cooperative research effort focused on autism under the Australian Government's Cooperative Research Centres (CRC) Program. We receive funding from a number of sources, including the Australian Government. Autism CRC is no longer part of, or associated with, the CRC Program.

autismcrc.com.au

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'.

Executive Summary

Why we did this work

The Australian Government has committed to the co-design and development of a National Autism Strategy (the Strategy) that is grounded in evidence and informed by the experiences of autistic people, their families and carers, and those who work to support them. This report describes the findings of the community views survey, research evidence review, and policy review relating to key service domains to be addressed in the National Autism Strategy. These **key service domains are: diagnosis; early intervention and support; education; employment; housing; justice; and health and mental health services.**

It is important that the community views, research findings, and policy review for each section are considered in combination and in their entirety; no single aspect should be considered in isolation.

What we did

The service domains were divided between Griffith University and Curtin University, aligning areas with the research expertise of each team.

- Curtin University, led by Professor Sonya Girder: Diagnosis, Early intervention and support, Education (post-secondary education and education systems), Employment and Housing
- Griffith University, led by Professor Dawn Adams: Health and mental health services (separated into two sections), Justice (including legal, policing, judicial, and custodial services), and Education (primary and secondary school).

For each service domain, three forms of research were undertaken to support a broad understanding. This consisted of:

- i) the “1,000 insights” survey; an online survey gaining perspectives of over 1,000 members of the autistic community, their families/carers, and people who work with them;
- ii) an umbrella review summarising research findings; and
- iii) a policy review summarising relevant federal, national, and state/territory level policy.

The “1,000 insights” **community views survey** was co-designed with the research team, autistic advisors, and Autism CRC staff. Within each service domain, people were asked four questions:

- What are three problems that autistic people experience within <service domain>?
- What do you think is causing these problems?
- What do you think could prevent or reduce these problems?
- What is working well, or has worked well, for autistic people within <service domain>?

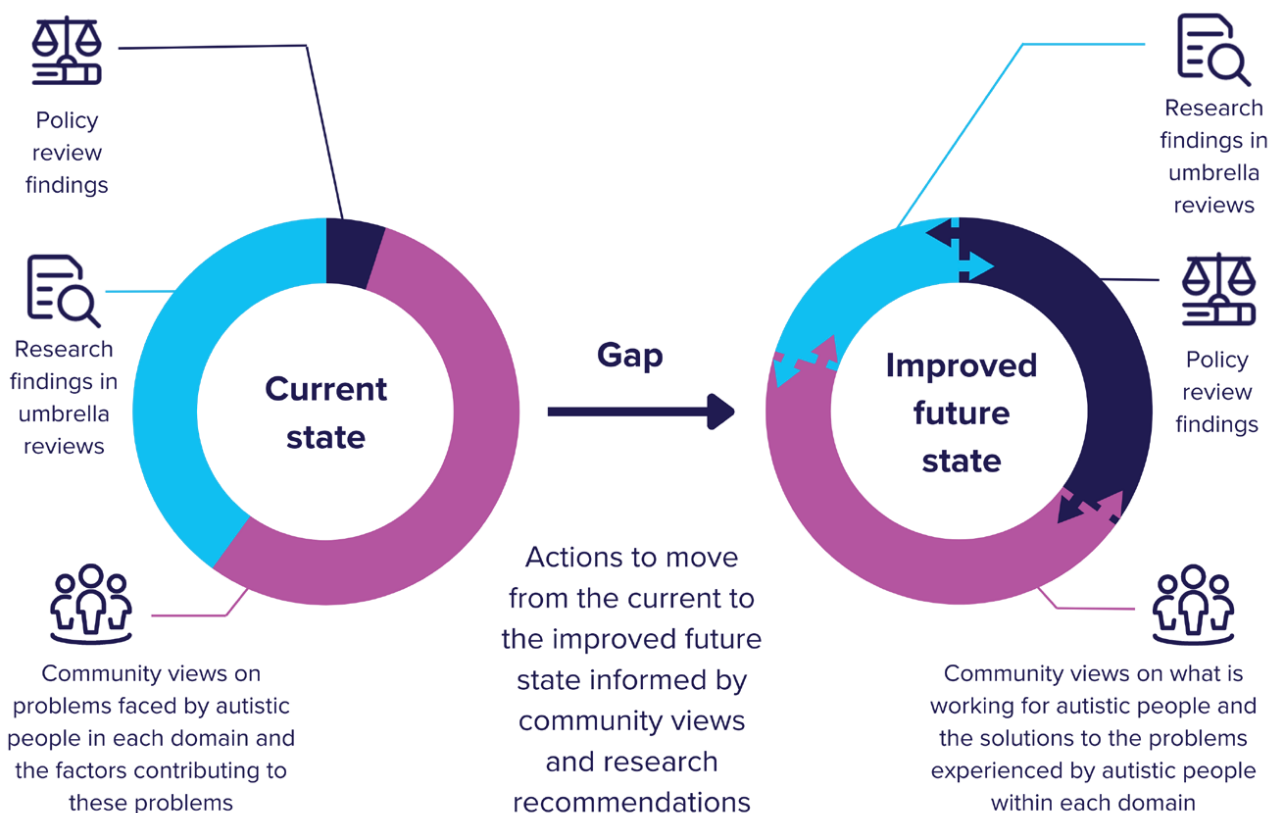
There were 1,018 responses to the community views survey. Almost half (42%) of the respondents were autistic; over half (56%) were parents, family members, or caregivers of autistic people. Respondents were also educational professionals (19%), allied health professionals (18%), mental health professionals (10%), and researchers (10%).

The **research review** used an umbrella review method to identify all the published systematic reviews of published articles related to the specific domain. Across the eight domains, over 16,000 systematic reviews were screened to identify the 185 systematic reviews relevant to the service domains within this report. Collectively these report on over 700 research studies and over 2,500,000 participants.

The **policy review** identified publicly available policies and guidelines relating to autism and/or broader disability. Relevant information was extracted and synthesised. Across the domains, 120 policies and guidelines were reviewed and synthesised.

The findings of each of the three forms of research (community views survey, research reviews and policy reviews) were combined to undertake a **gap** analysis. The first stage of the gap analysis provided a description of the *current state* (predominantly based upon the community views analysis but also some findings of the research review and policy review). The second stage then provides a description of an *improved future state* (based upon community views around what is working well, policy review, and some research review findings). The gap analysis process is depicted in Figure 1.

Figure 1: Gap analysis: Current to improved future state



What we found

A brief summary of the key findings for each service domain is presented below. Whilst each specific domain is presented separately in this report, the gap analysis identified a number of *needs* (i.e., areas for action and improvement) that were present across multiple domains. The key or overarching areas for change or improvement that cut across multiple domains are summarised in section 1.3.9.

Diagnosis

Survey respondents (545 respondents, including 237 autistic people) reported that difficulties are experienced by autistic people at all stages of the diagnosis process (before, during and after). The diagnostic process is long, confusing, deficit-based, and expensive, and there is a lack of professionals who follow the National Guideline for the Assessment and Diagnosis of Autism or those who use a neurodiversity affirming approach. Challenges with diagnosis were echoed in the research review.

The research review considered a range of other relevant topics including recommendations for clinicians, the use of clinical tools and processes to support a timely diagnosis of autism, and considerations to include in the assessment and diagnosis of autism.

Supporting the research review findings, the key policy (National Guideline for the Assessment and Diagnosis of Autism, currently being updated) provides specific guidelines on how to conduct a holistic, neurodiversity affirming and evidence-based assessment and diagnosis of autism across the lifespan, including the need to consider other important factors (e.g., age, intellectual capacity).

The gap analysis highlighted the clear need for improvements across the diagnosis process, including increasing the number of professionals with knowledge of autism able to diagnose, reducing financial barriers to diagnosis, ensuring a clear and equitable approach to diagnosis, and using a neurodiversity affirming approach. Ongoing research and continual evaluation is required to ensure diagnoses are made with the best available tools and processes, and to understand the diagnostic experiences and priorities of autistic people and their supporters, particularly those from marginalised groups.

Early intervention and support

The community views survey (completed by 350 respondents, including 115 autistic people) indicated that autistic people experience a number of challenges when trying to access early intervention and supports. These challenges include: a lack of timely access to support services linked to long waitlists, high costs of accessing services, lack of quality health professionals and trained staff who are competent and have an understanding of neurodivergence.

The research review indicated that a number of early intervention approaches have positive effects for autistic children, such as behavioural interventions, naturalistic developmental behavioural intervention, technology-based interventions, and cognitive behaviour intervention. However, most of the research literature does not consider the effect of the intervention on caregivers, the influence that the method of delivery had on the outcomes, or the influence of the individual characteristics of the child (e.g., age, co-occurring conditions).

The key policy related to early intervention and support is the National Guideline for the Assessment and Diagnosis of Autism (Whitehouse et al., 2018). The document outlines guiding principles and recommendations for the early intervention process that speaks to child and family-centred interventions, that are individualised, strength-based and neurodivergent affirming.

The gap analysis highlights the needs to improve access to a range of affordable early intervention services and supports, with professionals who have an increased level of autism knowledge and understanding. Families should also be provided with clear and correct information to support and advocate for their autistic family members.

Education

The community views survey (completed by 866 respondents, including 373 autistic people) and the primary/secondary education research review identified a lack of autism knowledge held by school staff and students, which then leads to insufficient provision of accommodations and supports for autistic students in educational settings. The community views also highlighted that the focus on neurotypical learning approaches (e.g., pedagogy and assessment; curriculum), and school environments and expectations (e.g., rules; attendance requirements) designed for neurotypical students make it challenging for autistic students to attend and/or achieve.

Although few primary/secondary education policies make specific reference to autism, those that did specify that: (a) the autism knowledge and understanding of staff and students could be supported, and (b) autistic students should have access to adjustments/accommodations at school. The gap analysis therefore highlighted a clear need to improve the level of autism knowledge and understanding of educators, as well as appropriate adjustments and accommodations, to support neurodiversity. There is also a need to consider the sensory environment in educational settings.

For postsecondary education, the research review showed that autistic students often feel prepared academically but have difficulties with daily living and social skills. Autistic students experience social, emotional, communication, and sensory difficulties which impact their postsecondary education and mental health. Poor self-advocacy skills make it difficult for autistic postsecondary students to access available supports. There is a lack of research that investigates the effectiveness and impact of interventions, supports, and programs (e.g., peer mentoring programs, mental health, and sensory interventions) on autistic students' outcomes relating to academic and personal changes over a longer period, including rigorous pre-post measures.

There is only one policy initiative related to autism that addressed parts of postsecondary education (the Australian Government Response to the Select Committee on Autism (report): Services, support, and life outcomes for autistic Australians). This policy initiative highlights the need for improvement of education for autistic people as part of the development of the National Autism Strategy and suggests that autistic postsecondary students' can be supported by increasing understanding among higher education staff, promoting autism-friendly campuses and information, and adopting autism inclusion and peer mentoring programs.

Employment

The community views survey (completed by 526 respondents, including 305 autistic people) identified that there were difficulties in finding, obtaining, maintaining, and progressing in employment for autistic people. A lack of education and awareness about autism in the workplace, potentially leading to bullying and discrimination, was seen as a primary barrier to employment for autistic people, as well as a lack of appropriate work environments and support for flexible working arrangements from employers. Providing supportive physical and policy environments, incentivising employers to hire autistic people, and matching job roles with autistic peoples' strengths were seen as ways to increase autistic employment.

The research review findings largely focused on evaluating interventions and supports for employment. Less research considered predictors of employment for autistic people, benefits of autistic employment, barriers and facilitators to the employment of autistic people, and international policy related to employment of autistic people. The research literature highlighted a need for further research on the experiences and needs of autistic people in the workplace, and neurodiversity framed supports and neurodivergent focused programs to increase employment and employment related skills. Limited policy documents were identified in relation to the employment of autistic people, with most presenting increasing autistic employment as a priority.

The gap analysis indicated a clear need to increase the autism knowledge of people within workplaces (employers and employees). This knowledge, in turn, could enhance employers' openness to employing autistic people, and supports an increase in accommodations and supports across the employment process (e.g., application, interview, and within the workplace) to support the employment of autistic people.

Housing and independent living

The community views survey (completed by 186 respondents, including 105 autistic people) indicated that autistic people encounter a number of challenges when trying to access housing. These include; a general lack of availability of social/public housing, difficulty accessing affordable private housing that is suitable to meet their sensory and spatial design needs, and a lack of adequate financial means and supports to sustain independent living and navigate the rental process.

The research review addressed considerations for housing design such as planning for easy navigation and sensory sensitivities to accommodate autistic people. Additionally, the policy review indicated that multiple federal and state housing policies highlighted funding availability through the NDIS for housing as well as the need to prioritise the availability, affordability and suitability of housing for people with disabilities.

Taken together, the gap analysis highlighted a need to ensure that there is a choice of accessible housing options available for autistic people, with people working in the sector increasing their knowledge of autism.

The justice system

The community views survey (completed by 166 respondents, including 86 autistic people) and the justice system research review identified a lack of autism knowledge held by people within the justice system as a clear problem. This lack of knowledge can lead to insufficient use of accommodations and supports, misinterpretation of the behaviours of autistic people, discrimination, and a system/process that is not appropriate for, or supportive of, autistic people.

Few justice system policies made specific reference to autism. Policies that did make specific reference highlight that a person's autism diagnosis should be considered when interpreting their behaviour within a justice setting, and that the environment should support accessibility. Policy also discussed specialist pathways (e.g., Assessment and Referral Court List) that seek to address underlying factors contributing to autistic people offending.

The gap analysis identified a clear need to increase the autism knowledge and understanding of people working in the justice system, and improving the identification of autistic people within this setting. There is also a need to provide appropriate supports and accommodations, assist with the development of an accessible and inclusive system, and reduce discrimination within the justice system. Further research into why autistic people enter the justice system, and the efficacy and use of specialist diversionary pathways is needed.

Mental health services

The community views survey (completed by 529 respondents, including 250 autistic people) and research review suggested that many mental health providers do not have sufficient knowledge of autism or its inter-relationship with mental health problems (or other diagnoses). This means that many providers do not know how to tailor their approaches to autistic clients or do not provide the accommodations or supports that would enable autistic people to access their service/s. Additionally, the limited availability of providers, long waiting lists and prohibitive cost lead to many autistic people not accessing mental health supports or having to wait a long time to do so. This lack of services and delay in accessing support for mental health challenges is particularly impactful for the autistic community given the research showing that significantly more autistic people than non-autistic people experience mental health challenges.

The policy review highlighted that mainstream services should be equipped to meet the needs of all autistic people, emphasising the need for autism-specific training of mental health professionals. There is also a need for more evidence-based mental health supports or interventions designed specifically for autistic people. Further research into how and why autistic people experience elevated rates of mental health problems, and a "mental health needs analysis" to evaluate both met and unmet mental health care needs for autistic Australians, will help to inform service provision into the future.

Physical health services

Similar to mental health services, both the community views survey (completed by 606 respondents, including 253 autistic people) and research review suggested that many physical healthcare providers do not have sufficient knowledge of autism, do not know how to tailor their approaches to autistic clients or do not provide the accommodations or supports that would enable autistic people to access their service. Additionally, the environment (e.g., sensory experience) of physical healthcare settings, the communication demands and the logistics of making appointments, reduces accessibility of healthcare services for autistic people. These can result in some people avoiding accessing physical healthcare, even when necessary. Over one quarter of autistic people who completed the community views survey felt that they were dismissed or not believed by healthcare providers. These problems with accessing physical healthcare are all in addition to the broader problems of long waiting lists, high costs, and a limited availability of providers.

The policy review highlighted the need for specialist training on how to support the needs of people with disabilities, which would include autistic individuals. Policy also recognises a need for supports and accommodations to be provided to autistic individuals to enable them to attend their healthcare appointments. International healthcare settings (e.g., United Kingdom) have both general and specialised training available for professionals who would benefit from more specific knowledge of autism, which align with a core capabilities and competencies framework for supporting autistic people. The gap analysis also highlights the need for more autistic people in healthcare settings, either as staff or on advisory boards, to ensure that autistic perspectives are incorporated throughout the healthcare service. To inform service provision in the future, further research is needed into how and why autistic people experience elevated rates of physical health problems, and a “physical healthcare needs analysis” to evaluate both met and unmet physical health care needs for autistic Australians.

Key needs; recommended areas for action and improvement across domains

The results of the community survey, research reviews, and policy reviews detailed in this report highlight areas of need, across a range of sectors, that are required to support better outcomes for autistic people. The following needs were noted in over half of the domains. These could be considered as priority areas to be addressed within all areas of the National Autism Strategy

- There is a need for a greater understanding about autism and all the diversity of its presentation within government, services, professionals, workplaces, and/or the community. This was noted within all domains.
- There is a need for adjustments, accommodations, and supports to be provided to enable autistic people equitable access to services. This was noted in 7 out of the 8 domains.
- There is a need for increased, timely, and equitable access to services (e.g. through more services, more providers, broader geographical access or locations). This was noted in three-quarters of the domains.
- There is a need for physical environments (e.g. schools, hospitals, court rooms) to be sensory considerate (e.g. by reducing sensory stimuli in environment). This was noted in half of the domains.
- There is a need to reduce the financial barriers to accessing services (e.g. through subsidisation, price caps etc.). This was noted in half of the domains.

Other needs noted within at least two domains were:

- There is a need for more co-produced research to understand the factors that contribute to autistic people needing to access services and supports (e.g. what leads to more autistic people experiencing more physical or mental health problems?).
- There is a need for more options and choice about services or settings that will best support autistic people, according to their needs and preferences.
- There is a need to ensure that autistic people feel safe, heard and believed by professionals within services.
- There is a need for more neurodiversity affirming approaches and acceptance of autism and neurodiversity.
- There is a need for clear, consistent, and equitable approach to autism assessments.

Whilst the findings reported in this document are in specific domains, **none of these domains exist in isolation**, and improvements in one area could lead to significant benefits in others. For example, if autistic people were able to receive their diagnosis at an earlier age (improvement in diagnosis services) and then receive supports or interventions which are aligned with their goals to promote well-being (early interventions or supports), these may lead to improvements in education and mental health in childhood, which relate to improved employment, post-school education and mental health outcomes. Similarly, if more teachers and school leaders received autism-specific training to promote inclusivity and acceptance of diversity in schools, as well as strategies to support students effectively (education), autistic people could be more successful at school, this would support participation in post-secondary education and employment, which in turn is associated with financial security. Teacher and school leader understanding of inclusivity and acceptance of diversity could also support changes in the attitudes and actions of non-autistic students towards autistic students, which could provide a societal shift in how autistic people are treated in the home, workplace (employment), healthcare, and other settings (e.g., the justice system). Such interactions highlight the importance of systems, supports and services for autistic people working together rather than in 'siloes', informed by the perspectives of autistic people and their supporters to ensure changes to services and systems are appropriate for autistic people.

What happens next?

The above needs are recommended areas for action and improvements which can be addressed within the National Autism Strategy. Given their breadth and impact, addressing these areas for action and improvement has the potential to redefine outcomes for autistic people across the lifespan. A commitment to such change will need to be driven by policy to enable and facilitate change through all levels of government, systems, organisations and professionals. The latter include researchers, autistic-led organisations and supporters of autistic people.

Stakeholders must therefore come together to address these issues nationally and genuinely collaborate to work towards a better future for autistic people in Australia. This is a **call to action for all those supporting autistic Australians** to commit to proactively address the needs identified above and make steps towards positive change in supports and service provision.

This work can help inform those guiding and developing the National Autism Strategy

This report is being provided to the Department of Social Services, so they (and other government departments) can use it to inform their work. Throughout the process of undertaking this project, we have presented the findings to the working groups who are supporting the Oversight council of the National Autism Strategy. We will continue to share the findings of this work with those involved in the National Autism Strategy whenever possible.

This work can help evaluate if the National Autism Strategy leads to “real change”

“However beautiful the strategy, you should occasionally look at the results.”

– Winston Churchill

This work provides a baseline upon which the outcomes of the National Autism Strategy can be evaluated, and its impact tracked. The community views survey can be repeated and the prevalence of the problems in each service domain compared to that in this report. This will help compare the experiences of autistic people and their supporters from before and after the strategy is implemented, therefore evaluating any “real change” experienced by the community. The research and policy reviews can also be updated to evaluated progress in specific areas relevant to the contents of the strategy.

This work can help inform those supporting autistic people across Australia

Although this work was conducted to help inform those developing the National Autism Strategy, the findings have importance and relevance for all of those supporting autistic people and their families across Australia, in a policy, service, personal or research capacity. It will require continued and meaningful collaboration across these areas, both at a Federal and state/territory level, to improve outcomes for autistic Australians. To ensure this work contributes to such processes and change, we will also publish the findings of this work in academic journals and present summaries to clinicians and researchers so that they can use this to inform and inspire their work in the future.

Our values



Inclusion

Valuing lived experience



Innovation

Solutions for long term challenges



Evidence

Truth in practice



Independence

Integrity through autonomy



Cooperation

Capturing opportunities together



AutismCRC

Independent national source of evidence for best practice



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