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

Final Report

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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.

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A note on terminology

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

Contents

Executive Summary 1

1. Introduction 10

1.1 Background 10

1.2 Aims 10

2. What we did 11

2.1 General methods 11

2.1.1 The "1,000 Insights" community views survey 11

2.1.2 Umbrella review 14

2.1.3 Policy review 15

3. What we found 16

3.1 Diagnosis 16

3.1.1 The "1,000" Insights" community views survey 16

3.1.2 Umbrella review 35

3.1.3 Policy and guideline review 39

3.1.4 Community views, research evidence, and policy/guideline gap analysis 41

3.2 Early intervention and support 46

3.2.1 The "1000 Insights" community views survey 46

3.2.2 Umbrella review: Early intervention and support services 63

3.2.3 Policy and guideline review 67

3.2.4 Community views, research evidence, and policy/guideline alignment and gap analysis 70

3.3 Education 75

3.3.1 The "1,000 Insights" community views survey 75

3.3.2 Umbrella review: Primary and secondary education 100

3.3.3 Policy and guideline review: Primary and secondary education 104

3.3.4 Research evidence and policy/guideline gap analysis 130

3.3.5 Umbrella review: Postsecondary education 130

3.3.6 Policy and guideline review: Postsecondary education 135

3.3.7 Community views, research evidence, and policy/guideline alignment and gap analysis 138

3.4 Employment 145

3.4.1 The "1,000 Insights" community views survey 145

3.4.2 Umbrella review 163

3.4.3 Policy and guideline review 170

3.4.4 Community views, research evidence, and policy/guideline alignment and gap analysis 174

3.5 Housing and independent living 179

3.5.1 The "1,000 Insights" community views survey 179

3.5.2 Umbrella review: Housing design 197

3.5.3 Policy and guideline review 203
3.5.4 Community views, research evidence, and policy/guideline alignment and gap analysis 207
3.5.5 Umbrella review: Independent living 212

3.6 Justice 217
3.6.1 The "1,000 Insights" community views survey 217
3.6.2 Umbrella review 232
3.6.3 Community views, research evidence, and policy/guideline alignment and gap analysis 251

3.7 Mental health services 258
3.7.1 The "1,000 Insights" community views survey 258
3.7.2 Umbrella review 283
3.7.3 Policy and guideline review 288
3.7.4 Additional information from literature reviews within other autism crc projects 301
3.7.5 Community views, research evidence, and policy/guideline alignment and gap analysis 301

3.8 Physical health services 307
3.8.1 The "1,000 Insights" community views survey 307
3.8.2 Umbrella review 326
3.8.3 Policy and guideline review 333
3.8.4 Community views, research evidence, and policy/guideline alignment and gap analysis 343

4. Summary and conclusion 350

4.1 Summary of identified needs across domains; areas for action or improvement 350
4.2 Limitations and considerations of the findings 353
4.3 Conclusion 354

List of tables

Table 1: Community views survey respondent demographics 13

Table 2: 10 most frequently reported problems experienced by autistic people and their family/carers in relation to diagnosis 18

Table 3: 13 most frequently reported factors causing problems experienced by autistic people and their family/carers in relation to diagnosis 23

Table 4: 9 most frequently reported factors that could prevent or reduce the problems experienced by autistic people and their family/carers in relation to diagnosis 29

Table 5: 6 most frequently reported factors that are working well, or have worked well, in relation to autistic people and their family/carers accessing diagnosis 33

Table 6: Umbrella review findings for diagnosis 36

Table 7: Policy and guideline review findings for diagnosis 39

Table 8: 10 most frequently reported problems experienced by autistic people and their family/carers in relation to early intervention and support services 48

Table 9: 10 most frequently reported factors causing the problems experienced by autistic people and their family/carers in relation to early intervention and support services 52

Table 10: 10 most frequently reported factors that could prevent or reduce problems experienced by autistic people and their family/carers in relation to early intervention and support services 56

Table 11: 10 most frequently reported factors that are working well, or have worked well, in relation to autistic people and their family/carers accessing early intervention and support services 60

Table 12: Umbrella review findings for early intervention and supports for autistic children 65

Table 13: Policy review findings for early intervention and supports for autistic children 68

Table 14: 10 most frequently reported problems experienced by autistic people in relation to education 77

Table 15: 10 most frequently reported factors causing the problems reported by autistic people in relation to education 83

Table 16: 10 most frequently reported factors that could prevent or reduce problems experienced by autistic people in relation to education 90

Table 17: 10 most frequently reported factors that are working well, or have worked well, for autistic people in education 95

Table 18: Umbrella review findings for primary and secondary education 102

Table 19: Policy and guideline review findings for primary and secondary education 107

Table 20: Umbrella review findings for postsecondary education 133

Table 21: Policy and guideline review findings for postsecondary education 136

Table 22: 10 most frequently reported problems experienced by autistic people in relation to employment . 147

Table 23: 13 most frequently reported factors causing the problems experienced by autistic people in relation to employment 151

Table 24: 11 most frequently reported factors that could prevent or reduce the problems experienced by autistic people in relation to employment 155

Table 25: 12 most frequently reported factors that are working well, or have worked well, in relation to autistic people accessing employment 160

Table 26: Umbrella review findings for employment 165

Table 27: Policy and guideline review findings for employment 171

Table 28: 11 most frequently reported problems experienced by autistic people in relation to housing 180

Table 29: 14 most frequently reported factors causing the problems experienced by autistic people in relation to housing 185

Table 30: 10 most frequently reported factors that could prevent or reduce the problems experienced by autistic people in relation to housing 190

Table 31: 11 most frequently reported factors that are working well, or have worked well, for autistic people in relation to housing 194

Table 32: Umbrella review findings for housing design 199

Table 33: Policy and guideline review findings for autism and housing....204

Table 34: Umbrella review findings for independent living....214

Table 35: 9 most frequently reported problems experienced by autistic people in relation to the justice system 219

Table 36: 8 most frequently reported factors causing the problems experienced by autistic people in relation to the justice system 223

Table 37: 8 most commonly reported factors that could prevent or reduce the problems experienced by autistic people in relation to the justice system....226

Table 38: 5 most frequently reported factors that are working well, or have worked well, in relation to autistic people accessing the justice system 230

Table 39: Umbrella review findings for justice 234

Policy and guideline review....239

Table 40: Policy and guideline review findings for justice....241

Table 41: 10 most frequently reported problems experienced by autistic people in relation to using or trying to access mental health services 260

Table 42: 10 most frequently reported factors causing the problems experienced by autistic people in relation to using or trying to access mental health services....267

Table 43: 10 most frequently reported factors that could prevent or reduce the problems experienced by autistic people in relation to mental health services 272

Table 44: 10 most frequently reported factors that are working well, or have worked well, in relation to autistic people using or trying to access mental health services 278

Table 45: Umbrella review findings for mental health services....285

Table 46: Policy and guideline review findings for mental health services 291

Table 47: 10 most frequently reported problems experienced by autistic people in relation to physical health services....309

Table 48: 10 most frequently reported factors causing the problems experienced by autistic people in relation to accessing physical health services 313

Table 49: 10 most frequently reported factors that could prevent or reduce the problems experienced by autistic people in relation to accessing physical health services 317

Table 50: 10 most frequently reported factors that are working well, or have worked well, in relation to autistic people accessing physical health services....322

Table 51: Umbrella review findings for physical health services 328

Table 52: Policy and guideline review findings for physical health services....335

Table 53: Needs (i.e. areas for action and improvement) identified in the gap analysis across each of the eight domainsThe other areas for action and improvement were: 352

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>?

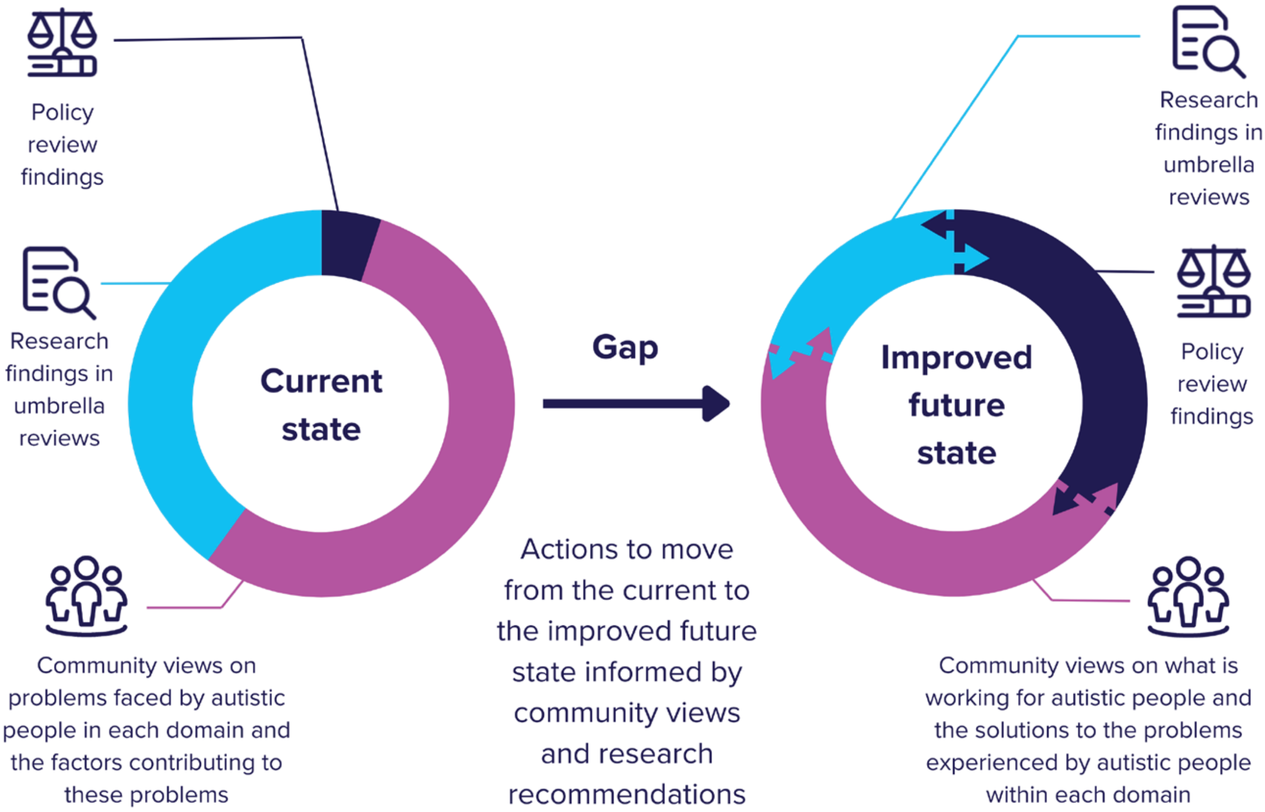
There were 1,018 responses to the community views survey. Almost half (42%) of the respondents were autistic; over half (56%) were parents, family members, or caregivers of autistic people. Respondents were also educational professionals (19%), allied health professionals (18%), mental health professionals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

1. Introduction

1.1 Background

The Australian Government has committed to developing a National Autism Strategy (the Strategy). They engaged Autism CRC to assist with developing this strategy, including conducting research and consultation activities in the initial phase of the strategy development process. This document outlines the activities related to (i) the community views survey which aimed to identify key issues related to the service domains; (ii) the review of the current evidence, practice, and policy landscape across a range of autism-related service domains and (iii) a gap analysis.

1.2 Aims

The aim of this project was to undertake a series of focused activities tailored towards the specific outcome of supporting the development of the Strategy. These activities focus on the following service domains:

- Diagnosis
- Early intervention and support
- Education (including post-secondary education and education systems)
- Employment
- Health and mental health services (separated into two sections)
- Housing
- Justice (including legal, policing, judicial, and custodial services).

For each domain there were four tasks:

1. To gain perspectives from the autistic and autism communities
2. To review the academic literature
3. To review federal, national, and state and territory policy relating to autism
4. Conduct a gap analysis, bringing together the findings from community, research, and policy to compare the current situation to desired or expected outcome.

2. What we did

2.1 General methods

This report focuses on seven service domains, aligned with those identified in the Select Committee (report): Autism services, support and life outcomes for autistic Australians. One of these domains (Health) was further divided to allow for a more thorough understanding of this topic area. This resulted in the following domains for review:

- Diagnosis
- Early intervention and support
- Education
- Employment
- Housing
- Justice (including legal, policing, judicial, and custodial services)
- Mental health services
- Physical health services.

To capture a broad understanding of each topic area, three approaches were taken, each of which is discussed in more detail in the following subsections.

1. The "1,000 insights" community views online survey to capture the perspectives of the autistic community and other stakeholders
2. Umbrella review of all systematic reviews relating to the service area (used to identify research gaps)
3. Policy review of all Australian federal, state, and territory policies and guidelines.

The findings of these three approaches were used to conduct a gap analysis, allowing identification of the current experiences of autistic people in relation to each domain and how this compares to the desired or expected state within policy or research. This information can inform the National Autism Strategy through informing the development and implementation of domain-specific or domain-general action plans which aim to achieve the desired outcomes.

2.1.1 The "1,000 Insights" community views survey

An online survey was used to capture the thoughts and perspectives of the autistic community and other relevant stakeholders (e.g., families/carers, teachers, health professionals) on each of the service domains listed above. This survey was co-designed with the research team, autistic advisors, and Autism CRC staff. The survey invited people to answer four questions for each of the service domains, with some aspects tailored to the specific domain:

1. What are three problems that autistic people experience within this service domain?
2. What do you think is causing these problems?
3. What do you think could prevent or reduce these problems?
4. What is working well, or has worked well, for autistic people within this service domain?

People sharing their insights were able to provide responses for as many service domains as they wished. Within each domain, the person answered the questions using their own words (i.e., they were not given tick boxes or predefined options to select from). This ensured the answers would come from the community rather than being those predefined by the research team and/or their advisors. In addition to the above questions, the survey garnered insight into the main issues that may make it challenging for autistic people to have their say in, and the preferred methods for providing insight and feedback on, the Strategy development. The community views survey is provided as Appendix B.

2.1.1.1 Ethics

The survey received full ethical approval from Griffith University on 3rd March 2023 (see Appendix A). Autism CRC listed the survey as live on their recruitment page on 13th March 2023, following which the Department of Social Services shared information with interested parties through their e-newsletter. The survey was also promoted through the Autism Centre of Excellence Facebook page on 13th March 2023. The promotion of the survey continued through until May 2023. The survey was closed at midnight on May 5th 2023.

2.1.1.2 Number of responses received

In total, 1,562 people clicked through to the survey, and 1,018 people selected one or more domains to comment on in the survey. Table 1 summarises the demographic details of the survey respondents. Note that respondents often identified within multiple groups (e.g., autistic and a parent/caregiver of an autistic child), so the total percentage is greater than 100%.

Table 1: Community views survey respondent demographics

Respondent characteristics	% of respondents (*N* = 1, 018)
Autistic individuals	42%
Parents, families or caregivers of autistic people	56%
Educational professionals	19%
Allied health professionals	18%
Mental health professionals	10%
Researchers	10%
Female	77%
Male	13%
Non-binary	7%
LGBTQIA+	17%
Physical disability	12%
Intellectual disability	2%
Part-time AAC user	3%
Full-time AAC user	0.1%
Non-speaking	0.1%
Living in home care or supported accommodation	0.4%
Aboriginal and/or Torres Strait Islander	2%
Culturally or linguistically diverse	8%

Given the relatively small number of people who identified as: (a) having a disability (physical or intellectual), (b) being an augmented and alternative communication user, (c) being non-speaking; (d) being Aboriginal and/or Torres Strait Islander; (e) being culturally or linguistically diverse, or (f) living in out of home care or supported accommodation, it is not possible to generalise the findings from this survey to all autistic people. The use of an online survey method also automatically excludes those without access to an appropriate device or those who do not have access to the internet. **Further work, using tailored approaches, is needed to learn from the experiences of these underrepresented groups.**

Respondents could choose to report on 0–8 service domains; 16% of respondents chose to report on one service domain, 15% on five domains, and 14% on six domains. The exact number of respondents to each service domain will be described in the relevant results section of this report. For context, the service domain with the most responses was education, where 866 respondents answered the questions. Autism diagnostic services, employment, mental healthcare, and physical healthcare each had 520–610 respondents. The service domain of early intervention had 350 respondents and the service domains of the justice system and housing each had fewer than 200 respondents.

2.1.1.3 Analysis of responses

The answers to each of the four questions were coded using inductive content analysis. Inductive means that the categories and codes were developed from the answers provided by the community; this means that the research team did not predefine any codes or hold any preconceived notions of what the responses should be, therefore allowing the community views to inform the findings. Content analysis involves reading every single response from every single respondent and systematically and objectively grouping similar responses together into codes (which represent a similar concept). Because people's experiences are so varied, this initially results in a large number of codes. Similar codes are then compiled into categories. To quantify the most common responses, the number of respondents who provided a response within each category is then calculated. To ensure that the categories discussed in this report represent the beliefs of the community rather than reflecting specific experiences, only those categories mentioned by 5% or more of respondents are included in this report.

For each question, respondents were asked to list up to three things; if they listed more than three, only the first three responses were coded. For this report, within each service domain, the 10 most frequently reported responses across the entire sample for each question are reported. On occasions when there were multiple responses with the same frequency in the tenth position, the total number of responses reported is greater than 10 to ensure all categories with equal frequencies in the tenth position are represented. The proportion of respondents within specific respondent groups (e.g., autistic adult, medical practitioner) are also reported to allow for similarities or discrepancies between respondent groups to be explored; this is important to consider when planning strategies so advice can be tailored. Response categories not within the 10 most frequently reported but deemed of high impact or of high importance are also reported.

2.1.2 Umbrella review

In technical terms, an umbrella review is a systematic review of all previous systematic reviews on a specific area. This is a useful approach as it provides a broad understanding of the research that has been conducted in an area, allowing for the strengths and limitations of this body of research to be considered. However, due to an umbrella review only reporting upon papers that are included within published systematic reviews, this method does not report on the very latest research findings.

Separate umbrella reviews were conducted for each service domain, with some being separated to allow a more discrete focus. Each umbrella review followed a standard process:

- Search of academic journal article databases using consistent search terms to identify all systematic reviews that have addressed a topic related to autism within the service domain (e.g., experiences of autistic people in the domain, knowledge of autism by service professionals)
- Careful consideration of each article identified to determine whether it is relevant for the review and, therefore, can meaningfully contribute to knowledge of the area
- Extraction of relevant information from each article to help identify key considerations and information about autism within the service domain.

Two of the umbrella reviews (Diagnosis; Early Intervention and Support) were conducted by A/Prof David Trembath (Griffith University), Dr Hannah Waddington (Wellington University), and colleagues as part of an Autism CRC project. These findings have been incorporated into this report. The remaining eight umbrella reviews were conducted specifically for this report.

Information from another Autism CRC project, “Quality of life and well-being of autistic individuals with complex support or communication needs”, was provided by Dr Kate Simpson. This was combined with the findings from the umbrella reviews undertaken specifically for this project and used to inform the Mental Health Service section of the report (Section 4.6). The information provided by Dr Simpson has been included within the Mental Health services appendix: Appendix J-5.

2.1.3 Policy review

Policy reviews provide understanding of the policies and guidelines that are present in each service domain. Although this project focused on topics related to autism within these service domains, policies and/or guidelines relating to disability were also identified as, in some cases, these policies may be relevant or applicable to the autistic and autism communities.

Each policy review used a standard process to ensure consistency across the domains:

- Review of Australian Federal Government websites to identify a comprehensive list of relevant professions and/or organisations (e.g., general practitioner, nurse, health care worker)
- Internet search to identify policy and/or guidelines relevant to autism and/or disability within the given professions/organisations. These searches were conducted at an Australian federal, national (e.g., national governing body, such as Australian Health Practitioner Regulation Agency), state, and territory level
- Extraction of relevant information within identified polices and/or guidelines.

Two of the policy reviews (Diagnosis; Early Intervention and Support) were previously conducted by A/Prof David Trembath (Griffith University), Dr Hannah Waddington (Wellington University), and colleagues as part of an Autism CRC project. The relevant findings from these reviews have been incorporated into this report. The current policy overview for the Education section has been undertaken specifically for this project; however, a full mapping of the Australian educational policy review is being undertaken in the separate Autism CRC project “Reducing Educational Barriers in Australian Schools”. All remaining policy reviews were conducted specifically for this report by the project teams (Griffith University or Curtin University).

3. What we found

3.1 Diagnosis

3.1.1 The “1,000” Insights” community views survey

A total of 545 respondents answered at least one of the questions on diagnosis. This included 237 autistic people and 338 family members or carers of autistic people. The 10 most frequently reported responses are reported within this section. On occasions when there were multiple responses with the same frequency in the tenth position, the total number of responses reported will be greater than 10 to ensure all categories with equal frequencies in the tenth position are represented.

The tables for each question describe the response categories (with example participant responses) in order of the most frequently reported to the least frequently reported. For each category, percentages are provided to indicate the proportion of a respondent group whose response reflected the specific category. These groups are (a) the entire sample (i.e., everyone), (b) autistic people, (c) family members/caregivers of autistic people, (d) mental health professionals; (e) medical and health allied professionals; and (f) all respondents not represented in one of the identified groups.

3.1.1.1 Problems experienced by autistic people in relation to diagnosis

A total of 545 respondents opted to answer this question on diagnosis. This included 237 autistic people and 338 family members or carers of autistic people. The problems experienced were coded into 12 categories, which fall under the following three broad areas:

- Before the diagnostic process starts, including getting referrals, knowing how to navigate the diagnosis process, getting hold of services or professionals who can initiate the diagnosis process, and the long wait time associated with accessing them
- During the diagnosis process, including securing the funds required for assessments and services, deficit-based manuals for diagnosis, health professionals not being specialised in diagnosing autism, not following the Autism CRC best practice National Guideline for Assessment and Diagnosis of Autism, not acknowledging a person or family’s concerns, and a very lengthy unclear process that is very taxing for the person or family pursuing a diagnosis
- After the diagnosis process, including misdiagnosis/over/under-diagnosis of autism, lack of support and information for those who receive a diagnosis and those who do not.

Table 2 ranks the 10 problems that autistic people experience in relation to the diagnosis service (based on the survey responses). The data are ranked from most frequently reported to least frequently reported problems across all respondents. The right-hand columns report the proportion of specific respondent groups that identified this as a problem. Respondents often identified within multiple groups (e.g., autistic and a parent/caregiver of an autistic child), so the number of respondents in subgroups exceeds the total number of all respondents.

Of note is that these data show that approximately:

Half of respondents highlight that it is hard to access diagnosis specialists, especially in remote areas.

1 in 2 respondents highlight that there are long wait times for starting the diagnosis journey.

1 in 3 respondents highlight that the cost of diagnosis is so high that many cannot pursue a diagnosis.

1 in 3 respondents highlight that health professionals' knowledge of autism is outdated, especially about female, adult and culturally diverse people.

Table 2: 10 most frequently reported problems experienced by autistic people and their family/carers in relation to diagnosis

Rank	Problems experienced by autistic people and their family/carers in relation to diagnosis	Direct insight	Respondents who stated this as a problem					
			All respondents *N* = 545	Autistic people n = 237	Family member/ caregiver of autistic person n = 338	Mental health professionals n = 66	Medical and allied health professionals n = 130	Other n = 222
1	**Access to health professionals who are experts in diagnosing autism, especially in remote places.**	*"Professionals with the ability to diagnose autism for adults are few and far between. Unless you live in one of the capital cities, your chances of finding one are low."* (ID 479)	54%	46%	55%	55%	52%	57%
2	**Long wait times for starting the diagnosis journey.** (e.g., wait times being longer in public system, many services not accepting new clients)	*"The waitlist for paediatrics is 3 years long and by the time the child is seen they are way past "early intervention"."* (ID 304)	52%	44%	57%	55%	50%	53%
3	**High costs of pursuing an autism diagnosis especially when going through the private system.** (e.g., those with financial problems miss out on diagnosis)	*"High cost of diagnosis and diagnostic services for people who statistically generally have a lower earning capacity. Waiting lists for diagnostic services NDIS not covering the cost of diagnosis."* (ID 1000)	40%	45%	40%	40%	44%	38%

Rank	Problems experienced by autistic people and their family/carers in relation to diagnosis	Direct insight	Respondents who stated this as a problem					
			All respondents *N* = 545	**Autistic people** n = 237	**Family member/ caregiver of autistic person** n = 338	**Mental health professionals** n = 66	**Medical and allied health professionals** n = 130	**Other** n = 222
4	**Health professionals with outdated knowledge of autism** (e.g., not recognising autism representations in females, adults, and those with less stereotypical behaviours, not recognising masking, ableist attitude towards autism, not recognising the vastness of the autism spectrum, trying to fit everyone into a box)	*"Amongst professionals, a lack of awareness, training and true understanding of the complex variability of autistic expression and experience, especially for female and less 'stereotypical' cases ** even and especially amongst those whose job is the diagnosis and treatment of autism. The outcome is the denial and exclusion of truly autistic people who must struggle on without the assistance and accommodations they so dearly need that diagnosis would have opened up."* (ID 1512)	30%	37%	32%	35%	33%	25%
5	**Gatekeepers' and educators (GPs, teachers) limited or outdated knowledge of autism** (e.g., GPs lack of understanding of autism leading to no or delayed referrals, teachers not picking up the signs in a student, dismissing parents' concerns, not knowing how to inform, how or when one can pursue diagnosis)	*"Dismissive and poorly educated GPs rejecting referrals for diagnosis because of their incorrect assumptions (i.e., autistic people can't make eye contact, girls aren't autistic, autistic people don't have the capacity to maintain relationships or careers, etc)."* (ID 246)	9%	11%	9%	6%	9%	8%

Rank	Problems experienced by autistic people and their family/carers in relation to diagnosis	Direct insight	Respondents who stated this as a problem					
			All respondents *N* = 545	Autistic people n = 237	Family member/ caregiver of autistic person n = 338	Mental health professionals n = 66	Medical and allied health professionals n = 130	Other n = 222
6=	**Limited funding or financial support opportunities as pursuing a diagnosis is very expensive** (e.g., access to NDIS funding, medical rebates)	*"Providers unwilling to help low-income people who feel they have autism get a diagnosis so that they can become a participant of NDIS and get the help they need."* (ID 153)	8%	8%	8%	8%	0%	8%
6=	**Autism diagnosis manuals are deficit-based and are not co-designed with autistic individuals.** (e.g., outdated diagnosis manuals, focusing on stereotypical behaviours, extremely pathologising, not accounting for autistic strengths)	*"The DSM5 is extremely pathologising and deficit based. It makes things difficult for clinicians using it if people are autistic but may not be demonstrating at that moment enough deficit even though in other situations or times they may. And it doesn't account for autistic strengths at all making it quite a traumatic experience to go through for many autistic people."* (ID 90)	7%	10%	8%	7%	6%	6%
6=	**Health professionals not following the National Guideline for the Assessment and of Autism, resulting in miscommunication between the multidisciplinary team, misinforming families, not following a unanimous diagnosis pathway.** (e.g., inconsistent standards, differing opinions, the diagnosis pathway is confusing, assessments and the reports are vastly different)	*"Maintaining diagnosis due to demands that lead to Autistic burnout living."* (ID 1330) *"Different diagnostics services will give different answers. Autistic people can have huge fluctuations in mood and it affects the diagnosis."* (ID 818)	6%	4%	4%	7%	9%	6%

Rank	Problems experienced by autistic people and their family/carers in relation to diagnosis	Direct insight	Respondents who stated this as a problem					
			All respondents *N* = 545	Autistic people n = 237	Family member/ caregiver of autistic person n = 338	Mental health professionals n = 66	Medical and allied health professionals n = 130	Other n = 222
6=	**Lengthy diagnosis pathway** (e.g., long wait and see period, complexity due to presence of other co-occurring conditions)	*"Takes years to get a formal diagnosis and lots of steps and different health professionals to go through."* (ID 1053)	6%	5%	8%	8%	8%	5%
6=	**Misdiagnosis or over/under diagnosis of autism, with some health professionals pushing for an autism diagnosis.** (e.g., health professionals not spending enough time to accurately assess a person, some just diagnose for NDIS funding, making it sound like autism)	*"Many professionals do not understand the vastness of the spectrum. They are trying to get people with Autism to fit into the box for "Autism". They cannot see that everyone with Autism is different just like all neuro**typical persons have their differences. Professionals are too quick to diagnose any slight difference as Autism so that families can get access to NDIS Funding. This affects the people that really need the funding support."* (ID 1303)	6%	7%	6%	8%	8%	6%

3.1.1.2 Factors causing the problems experienced by autistic people in relation to diagnosis

A total of 471 respondents opted to answer this question on diagnosis. This included 209 autistic people and 285 family members or carers of autistic people. The factors that respondents felt were causing or leading to the problems experienced by autistic people with diagnosis were coded into 13 categories, each falling under six broad areas:

- The services cannot meet the demand, and it is difficult to access services and health professionals trained with autism and its nuances, leading to very long wait times
- Lack of subsidisation or funding
- Outdated and deficit-based understanding of autism
- Lack of a clear, unified, standardised and collaborative approach to diagnosis, knowing when, how or why to pursue a diagnosis
- Bureaucracy covering diagnosis and privatisation of the diagnostic process
- Raising awareness about autism and its associated needs and strengths.

Table 3 ranks the 13 most commonly reported factors that respondents felt were causing the problems that autistic people experience in relation to diagnosis reported above. The data are ranked from most frequently reported to least frequently reported problems across all respondents. The right-hand columns report the proportion of specific respondent groups that identified this as a problem.

Importantly, these data show that approximately:

1 in 3 respondents stated that the problems were due to a lack of government funding, subsidisation and financial support for pursuing an autism diagnosis.

1 in 3 respondents reported that the problems were due to a shortage of trained specialist who can support diagnosis.

1 in 5 respondents stated that the health professionals’ knowledge of autism is outdated.

Table 3: 13 most frequently reported factors causing problems experienced by autistic people and their family/carers in relation to diagnosis

Rank	Factors causing the problems experienced by autistic people and their family/carers in relation to diagnosis and sample quote from responses	Direct insight	Respondents who stated this as a problem					
			All respondents *N* = 471	Autistic people n = 209	Family member/ caregiver of autistic person n = 285	Mental health professionals n = 66	Medical and allied health professionals n = 130	Other n = 222
1=	**Issues with subsidisation or funding** (e.g., there is lack of funding such as NDIS support or medical rebates)	*"Not sufficient fully funded services for parents to take children for assessment and diagnosis."* (ID 1227)	35%	15%	22%	36%	44%	48%
1=	**Lack of trained specialists, services and resources for diagnosis** (e.g., hard to access health professionals, many tell families they have closed their books for the year)	*"Not enough people able to diagnose."* (ID 207) *"Not enough providers with specialised skills."* (ID 558)	35%	13%	21%	36%	33%	32%
3	**Health professionals' outdated understanding of autism** (e.g., health professionals' knowledge based on stereotypical symptoms such as eye contact, they are not familiar with female presentations)	*"Medical professionals having a pre-set belief of what an autistic person should present with for a diagnosis. e.g. pre-set belief of seeing features such as hand flapping, spinning or extreme sensory seeking behaviours as part of the diagnosis and not understanding how autism can present very differently along a spectrum."* (ID 995)	21%	12%	14%	22%	18%	31%

Rank	Factors causing the problems experienced by autistic people and their family/carers in relation to diagnosis and sample quote from responses	Direct insight	Respondents who stated this as a problem					
			All respondents *N* = 471	Autistic people n = 209	Family member/caregiver of autistic person n = 285	Mental health professionals n = 66	Medical and allied health professionals n = 130	Other n = 222
4	**Outdated and deficit-based diagnostic manuals, resources and guidelines** (e.g., the diagnostic manuals have not been updated for a long time, guidelines and assessments are based on old-fashioned views of autism)	*"Many practitioners rely solely on assessment tools that have not been updated to reflect DSM-5 diagnostic criteria. They continue to hold diagnostically incorrect views, such as that you cannot be Autistic if you make eye contact, have empathy, or are social. This is causing significant harm through lack of correct identification for referral for assessment and misdiagnosis if a person presents for Autism assessment."* (ID 1330)	13%	8%	7%	8%	11%	16%
5	**Diagnostic services struggle to meet the current demand** (e.g., not enough health professionals trained with diagnosis)	*"Clearly there are not enough providers of government and private diagnostic services if it takes this long to be diagnosed."* (ID 312)	12%	3%	7%	8%	9%	11%
6	**High cost of an autism diagnosis** (e.g., the expenses related to assessments and then writing the reports being high, those with lower socio-economic status especially adults cannot access diagnosis)	*"They [families/autistic adults] have to pay for the diagnostic process themselves and all of the therapy until the funding is available. This funding also may not be enough."* (ID 170)	11%	6%	7%	10%	7%	3%

Rank	Factors causing the problems experienced by autistic people and their family/carers in relation to diagnosis and sample quote from responses	Direct insight	Respondents who stated this as a problem					
			All respondents *N* = 471	Autistic people n = 209	Family member/ caregiver of autistic person n = 285	Mental health professionals n = 66	Medical and allied health professionals n = 130	Other n = 222
7=	**Lack of trained autistic or autistic-informed health professionals** (e.g., inadequate training, not specialised in diagnosis, recognising more subtle presentations especially in females)	*"There are less opportunities to become a psychologist. When there are less psychologists there are less specialising in autism, thus the ones available are overwhelmed with clients."* (ID 758)	8%	4%	5%	7%	2%	1%
7=	**Community's lack of awareness about autism and its representations, especially in females and adults** (e.g., families or educators not recognising the signs, old fashioned perspectives, lack of acceptance and awareness in the society)	*"General embarrassment in the community to talk about "being different" Fear that if something is identified, it will make it worse. General lack of knowledge concerning autism with people "who should know" ie child care, teachers, health professionals etc."* (ID 452)	8%	4%	5%	8%	2%	5%
9	**Lack of unified, standardised and collaborative approach** (e.g., inconsistencies in the system, poor communications within a multidisciplinary diagnosis team)	*"A lack of unified approach to diagnose and support ASD. A lack of accountability and no regulatory oversight. Accountability needs to be genuine."* (ID 616)	6%	3%	3%	7%	7%	5%

Rank	Factors causing the problems experienced by autistic people and their family/carers in relation to diagnosis and sample quote from responses	Direct insight	Respondents who stated this as a problem					
			All respondents N = 471	Autistic people n = 209	Family member/ caregiver of autistic person n = 285	Mental health professionals n = 66	Medical and allied health professionals n = 130	Other n = 222
10=	**Lack of a government strategy, leading to bureaucracy and privatisation of the diagnosis process** (e.g., some just take advantage of the long waitlist in public to charge families more, elitism, bureaucracy in the system)	*"The lack of action by the previous federal government in adequately funding and staffing the mental health system or making any attempt to address the ongoing problems and failings within the mental health and disability systems as clearly identified by thousands of people including experts in these areas and various enquires and parliamentary committee reviews."* (ID 1440)	5%	3%	4%	11%	4%	14%
10=	**A need for training more health professionals with autism diagnosis** (e.g., not enough health professional experts in diagnosis, train other professions to support diagnosis)	*"Shortage of specialists and the time and cost associated with psychologist training and accreditation (I left a psychology degree due to the exorbitant amount I was going to have to pay for supervision)."* (ID 144)	5%	2%	2%	7%	11%	10%
10=	**Unclear diagnosis process: Knowing when, how or why to get diagnosed** (e.g., no idea when to start the diagnosis and who to contact)	*"[Diagnostic services] do not advertise they are able to do autism diagnosis, you have to contact Autism organisations to find out who they are. The process is not made clear to carers or the autistic person. Once diagnosed, the provider does not have any contacts for further help in terms of services available and any government assistance."* (ID 915)	5%	2%	2%	5%	7%	1%

Rank	Factors causing the problems experienced by autistic people and their family/carers in relation to diagnosis and sample quote from responses	Direct insight	Respondents who stated this as a problem					
			All respondents *N* = 471	Autistic people n = 209	Family member/ caregiver of autistic person n = 285	Mental health professionals n = 66	Medical and allied health professionals n = 130	Other n = 222
10=	**Very long wait times to access specialists** (e.g., long queues to access health professionals, long waiting period in the public system)	*“waiting times with public health can be 6-12 months which is an enormous long time for developing children.”* (ID 1199)	5%	1%	3%	5%	2%	0%

3.1.1.3 Factors that could prevent or reduce the problems experienced by autistic people in relation to diagnosis

A total of 387 respondents opted to answer this question on diagnosis. This included 164 autistic people and 233 family members or carers of autistic people. The factors that respondents identified as preventing or reducing the problems experienced by autistic people with diagnosis were coded into nine categories. These categories fall under the following five broad areas:

- Government funding and financial support
- Training more health professionals and updating them about the nuances of autism diagnosis
- Updating the diagnosis manuals/guidelines to be neurodiverse affirming and have criteria for adult diagnosis
- Providing clear and uniform diagnosis based on evidence (the National Guideline for the Assessment and Diagnosis of Autism)
- Increase awareness of autism and its diverse representations.

Table 5 ranks the nine most commonly reported factors that respondents reported could prevent or reduce the problems that autistic people experience in relation to accessing diagnosis reported above. The data are ranked from most frequently reported to least frequently reported problems across all respondents. The right-hand columns report the proportion of specific respondent groups that identified this as a problem.

Importantly, these data show that there were clear predominant factors highlighted by respondents:

More than half of the respondents stated that government funding and financial support for diagnosis could prevent or reduce the problems experienced by autistic people in relation to diagnosis.

1 in every 3 respondents identified that training health professionals with the nuances of autism, especially for diagnosing females and adults could prevent or reduce the problems experienced by autistic people in relation to diagnosis.

Table 4: 9 most frequently reported factors that could prevent or reduce the problems experienced by autistic people and their family/carers in relation to diagnosis

Rank	Factors that could prevent or reduce the problems experienced by autistic people and their family/carers in relation to diagnosis	Direct insight	% who stated this as a problem					
			All respondents *N* = 387	Autistic people n = 164	Family member/ caregiver of autistic person n = 233	Mental health professionals n = 66	Medical and allied health professionals n = 130	Other n = 222
1	**Government funding, financial support or medical rebates** (e.g., Medicare subsidies for assessments, reimbursement through NDIS, rebate on assessments)	*"More funding provided to diagnosis ASD for better access for vulnerable communities."* (ID 616)	53%	60%	55%	42%	33%	32%
2	**Training health professionals with the nuances of autism** (e.g., symptoms in females and adults, masking)	*"All healthcare professionals need to be trained about autism so that they can guide people appropriately."* (ID 18)	33%	41%	33%	18%	12%	20%
3	**Increase the number of health professionals qualified to diagnose autism** (e.g., train more health professionals)	*"Increase workforce numbers and capabilities linked to need and location."* (ID 141)	13%	9%	13%	9%	8%	7%
4	**Enable more health professionals to be involved in diagnosis process** (e.g., having other professions such as general psychologists and OTs trained and accredited)	*"Access to enough psychologists for assessments and therapies because only a small number of psychologists are endorsed "clinical" and by limiting assessments to only "endorsed" clinical or other psychologists, it is damaging for the general public… Amend the Autism Research recommendations to advise ALL psychologists can conduct autism assessments* (ID 555)	12%	7%	12%	8%	6%	5%

Rank	Factors that could prevent or reduce the problems experienced by autistic people and their family/carers in relation to diagnosis	Direct insight	% who stated this as a problem					
			All respondents *N* = 387	Autistic people n = 164	Family member/ caregiver of autistic person n = 233	Mental health profession-als n = 66	Medical and allied health profession-als n = 130	Other n = 222
5=	**Updating the diagnosis manuals/ guidelines to be neurodiversity affirming and have criteria for adult diagnosis** (e.g., manuals that consider female representations, not deficit-based, consider diversity of symptoms)	*"Fixing the DSM to add a new diagnosis for people who are diagnosed in adulthood."* (ID 40)	8%	10%	8%	5%	0%	4%
5=	**Providing clear and uniform diagnosis process based on evidence-based practices, such as the National Guideline for the Assessment and Diagnosis of Autism** (e.g., guidelines for assessment tools, standardised practices, national and international guidelines)	*"Follow the international standard of autism diagnosis"* (ID 426) *"Have clear and readily available guidelines."* (ID 47)	8%	6%	6%	4%	3%	4%

Rank	Factors that could prevent or reduce the problems experienced by autistic people and their family/carers in relation to diagnosis	Direct insight	% who stated this as a problem					
			All respondents *N* = 387	Autistic people n = 164	Family member/ caregiver of autistic person n = 233	Mental health profession-als n = 66	Medical and allied health profession-als n = 130	Other n = 222
5=	**Increase awareness of autism and its representations in community** (e.g., training parents and teachers to recognise the signs, autism awareness campaigns)	*"A top-down culture change that is precipitated by open communication about differences. Changes to policies and procedures affected by the employee lifecycle. Opening up a channel for employees with neurodiversity (or disability in general) where there is forum for constant communication to senior levels of management. Awareness training for all would be- or already are- managers, regardless of whether their employees have disclosed disability."* (ID 1415)	7%	8%	8%	8%	2%	4%
8	**Tertiary education providers to train and support more students** (e.g., developing courses or diplomas that support experts for diagnosing autism)	*"Fund tertiary education providers to train more students in neurodiversity paediatrics."* (ID 129) *"Universities need to look at the skills gap in training psychologists qualified to diagnose."* (ID 312)	6%	5%	6%	7%	2%	2%
9	**Support students interested in professions in diagnosis** (e.g., financially support tertiary students, provide incentives)	*"Include supervision as part of psychology degree programs. Don't force psych graduates to have to fight to find a supervisor who then charges them half a year's salary when they haven't even started earning a cent yet."* (ID 144)	5%	6%	5%	2%	2%	2%

Note. *all other groups that have not been identified separately

3.1.1.4 Factors that are working well, or have worked well, for autistic people in relation to diagnosis

Overall, 381 respondents replied to this question. This included 226 autistic people and 229 family members or carers of autistic people. From these responses, the factors that, when available, are reported to be working well, or have worked well, for autistic people in relation to diagnosis were coded into six categories, which fall under the following broad areas:

- When knowledgeable and informed health professionals, familiar and updated with the nuances of autism diagnosis, are available
- “Do not know” or nothing is/has worked well
- When families can access funding
- When they are already in connection with a multidisciplinary team
- When the health professionals acknowledge neurodiversity.

Table 6 ranks the six most commonly reported factors that respondents reported to be working well, or have worked well, for autistic people in relation to diagnosis. The data are ranked from most frequently reported to least frequently reported factors that are working well across all respondents. The right-hand columns report what proportion of specific respondent groups reported this as a factor that is working or has worked well.

Importantly, these data show that approximately:

1 in 5 respondents expressed that when there are knowledgeable and informed health professionals who are familiar with the nuances of autism, the diagnosis works well for autistic people.

Table 5: 6 most frequently reported factors that are working well, or have worked well, in relation to autistic people and their family/carers accessing diagnosis

Rank	Factors that are working well, or have worked well, in relation to autistic people and their family/carers accessing diagnosis	Direct insight	Respondents who stated this as a problem					
			All respondents *N* = 387	Autistic people n = 164	Family member/ caregiver of autistic person n = 233	Mental health professionals n = 66	Medical and allied health professionals n = 130	Other n = 222
1	**Knowledgeable and informed health professionals who are familiar with the nuances of autism** (e.g., representations in females, those with less stereotypical behaviours, autism is not about eye contact)	*"Medical and allied health professionals who are well trained and up to date with best practice, evidence-based diagnostic criteria of autism."* (ID 822)	18%	20%	14%	8%	6%	5%
2	**Nothing has worked, don't know**	*"Nothing, this system is chaotic and there are so many stressed families waiting for answers."* (ID 1492)	15%	16%	15%	6%	5%	8%
3	**Access to NDIS funding, though very limited** (e.g., NDIS funding for some assessment sessions or health professional visits)	*"Free government service which provided a quick pathway to accessing the NDIS while waiting for a formal diagnosis, noting this is only available to children seven years and under."* (ID 1162)	10%	5%	10%	6%	8%	4%
4	**Some private service providers and limited organisations who are supportive of neurodiversity** (e.g., supporting costs, being neurodiversity affirming)	*"Neurodiversity-affirming services are making a real difference to how the diagnostic process is experienced."* (ID 1192)	7%	5%	7%	2%	5%	3%

Rank	Factors that are working well, or have worked well, in relation to autistic people and their family/carers accessing diagnosis	Direct insight	Respondents who stated this as a problem					
			All respondents *N* = 387	Autistic people n = 164	Family member/ caregiver of autistic person n = 233	Mental health professionals n = 66	Medical and allied health professionals n = 130	Other n = 222
5=	**When families or autistic people are already part of an established functioning multidisciplinary team** (e.g., already working with a multidisciplinary team who work collaboratively and communicate well)	*“When the supportive network is good (the GP, counsellor, existing Psychologist), there is a natural flow into arranging diagnosis.”* (ID 1040)	5%	2%	5%	3%	3%	1%
5=	**Neurodivergent health professionals or those who are neurodiversity affirming** (e.g., neurodivergent psychologist with lived experience, health professionals who acknowledge diversity and do not focus on deficits)	*“There is a small but growing segment of neurodivergent professionals specifically serving the neurodivergent community, and a properly trained neurodivergent professional will in general provide much better outcomes than a neurotypical professional without lived experience.”* (ID 246)	5%	8%	4%	2%	3%	2%

3.1.2 Umbrella review

This section will present a summary of the umbrella review conducted by Waddington and colleagues (in preparation) relating to diagnosis of autism, rather than duplicating their work. The umbrella review included a total of 16 reviews, with the search strategy and search results provided in Appendix C-1 and Appendix C-2. Of the 16 included reviews, one was led by an Australian author. All included reviews were written in the last 5 years (between 2018 and 2022).

The information and findings from the included reviews are summarised in the subsections below. When reporting on the number of people or participants in the review, this will be represented as n = [number of participants]. When reporting on the number of reviews that considered a topic, this will be represented as k = [number of reviews].

3.1.2.1 Participants within included reviews

Half of the reviews (k = 8) included studies that involved individuals with an autism diagnosis (including children, adolescents, and adults), or those who were likely to receive an autism diagnosis. Studies including parents and/or family members (including mothers, fathers, grandparents, and aunts) were included in eight reviews. Seven of the reviews included clinicians involved in assessment, diagnosis, and/or provision of supports for autism. Only six of the included reviews reported the total number of included participants, which ranged between 342 and 120,540 participants.

3.1.2.2 Quality of included reviews

The quality of the included reviews was assessed using a modified version of the CACSRRS (Joanna Briggs Institute, 2020). For the included meta-analyses, scores ranged between 5 and 7 out of 11. For the 13 narrative syntheses, scores ranged between 2 and 10 out of 10 (mode = 8). Seven of the reviews (44%) were considered "high quality" because they met ≥ 80% of the items, and the remaining nine reviews (56%) were considered "low quality". The only review to score maximum points was conducted by Legg et al. (2019).

3.1.2.3 Topics of included reviews

The included reviews covered a range of topics, with some reviews covering more than one. These topics included: recommendations to guide practitioners in assessing and diagnosing autism (k = 5), clinical tools and processes that contribute to a timely diagnosis of autism (k = 9), considerations regarding personal and environmental factors in the assessment and diagnosis of autism (k = 4), and the views and experiences of autistic and autism communities about diagnosis (k = 6). The key findings for each topic are presented in Table 6.

3.1.2.4 Research gaps

The reviews identified several research gaps, which are combined with research gaps identified by the authors of this report and summarised in Table 6. In brief, further high-quality research is needed to continually improve clinician tools and processes, including evaluation of diagnostic tools (especially with minority groups) and diagnostic measures conducted via telehealth. Research exploring the views and experiences of stakeholders is needed, especially those underrepresented in the research.

Table 6: Umbrella review findings for diagnosis

Topic	Number of reviews on topic; citations	Key findings	Key research gaps identified
Clinical tools and processes	k = 9 (Clarke & Fung, 2022) (Ellison et al., 2021) (Dorlack et al., 2018) (Guan et al., 2022) (Howes et al., 2021) (Lebersfeld et al., 2021) (Loubersac et al., 2021) (Meimei & Zenghui, 2022) (Valentine et al., 2021)	**Clinician training** • Autism training programs increased physician knowledge and self-efficacy related to the care of autistic patients; only short-term changes to autism assessment referral rates were noted • Training of primary care physicians to diagnose autism may be suitable and reduce wait times for accessing diagnosis and supports **Telehealth and autism diagnosis** • There is emerging evidence to suggest telehealth autism diagnoses' sensitivity and specificity • Telehealth shows promise for autism diagnoses, with some evidence for the benefit to user experience and economic impacts • Available telehealth methods for autism diagnoses include pre-recorded and live video observations of the person being assessed **Assessment tools** • Evidence shows good sensitivity and specificity of diagnostic instruments, such as the ADOS-2 and ADI-R **Diagnostic process** • Facilitators, such as the use of multidisciplinary teams and clear referral processes, were identified in the diagnostic process • Barriers, such as limited time, long wait times, lack of professional and parental knowledge, and limitations of assessment tools, were identified in the diagnostic process • Diagnosis is complicated by the range of presentations of autism within different groups, discrepancies between clinical judgement and standardised tools, and pressure to diagnose for access to services • Clinicians should understand the factors that contribute to the age at which a diagnosis may be made, to potentially detect autism where it might otherwise have been missed	• More research is required to develop strategies and programs to change physician behaviours related to autism diagnosis and referral • Current research regarding primary care physicians diagnosing autism is limited and of low-moderate quality; more research is required before this can be recommended in clinical practice • Further high-quality research about the clinical effectiveness of using telehealth in autism diagnosis (including evaluating specific tools) is required • Further evaluation of diagnostic tools, particularly in clinical (non-research) contexts and with minority groups is required • Differences in diagnostic processes between countries should be understood • Perspectives on the diagnostic process should be sought to understand its impact on outcomes for autistic people, not just system efficiency

Topic	Number of reviews on topic; citations	Key findings	Key research gaps identified
Views and experiences	k = 6 (Boshoff et al., 2019)* (Brown et al., 2021) (Howes et al., 2021) (Legg & Tickle, 2019) (Lockwood Estrin et al., 2021) (Rivera-Figueroa et al., 2022)	• The diagnostic process can be confusing, and individuals may not feel heard or validated by clinicians • The diagnostic process can be a starting point down a pathway to receiving supports, but there are also large barriers to service availability and access • The diagnostic process is a time of significant emotional impact and adaptation to a new situation; parents require their emotional, informational, and relational needs to be met • Delivery of a diagnostic decision requires sensitivity and provision of education to families and individuals • Diagnosis of women and girls with autism appears to include additional barriers and frustrations • Culture and ethnicity have a significant impact on the experience of individuals and their families • Compared to white families, there is reduced access to information, more inaccurate beliefs about autism, and more negative interactions with healthcare providers for culturally and linguistically diverse populations	• More understanding is needed about the experiences of stakeholders who are less commonly represented in current research (e.g., fathers, teachers, clinicians) • Additional work should explore the causes of individuals and families' negative experiences as part of the diagnostic process • More culturally and linguistically diverse individuals should be included in research about autism and the experience of the diagnostic process • Studies should also capture more detailed demographic data to understand differences between groups • Future research should include collaboration with community leaders and gatekeepers to ensure minority groups are involved in research
Recommendations to guide practitioners	k = 5 (Boshoff et al., 2019)* (Clarke & Fung, 2022) (Legg & Tickle, 2019) (Lockwood Estrin et al., 2021) (Valentine et al., 2021)	• Clinicians need to understand the experiences and meet the needs of individuals and families • Clinicians require knowledge about the presentation of autism in different populations in order to provide accurate diagnoses	• Further research on the presentation of autism in populations such as females is required to improve clinical practice

Topic	Number of reviews on topic; citations	Key findings	Key research gaps identified
Personal and environmental factors	k = 4 (Lockwood Estrin et al., 2021) Loubersac et al., 2021) Sainsbury et al., 2022) (van't Hof et al., 2020)	A range of personal and environmental factors affect a person receiving an autism diagnosis • Age • Gender • Co-occurring conditions (particularly ADHD, social communication delay, and intellectual disability) • Race/ethnicity • Cultural background	• Further research is required to understand the relationship between personal and environmental factors and the ability to receive a diagnosis and the age at which this occurs • More inclusion of minority groups in high-quality autism research is required

* Denotes review led by Australian author.

3.1.3 Policy and guideline review

In the area of diagnosis of autism, the focus is on the National Guideline for the Assessment and Diagnosis of Autism (Whitehouse et al., 2018). This guideline is currently being reviewed and updated by the Autism CRC, with the draft revised version released for community consultation in May 2023 (see Table 7).

Table 7: Policy and guideline review findings for diagnosis

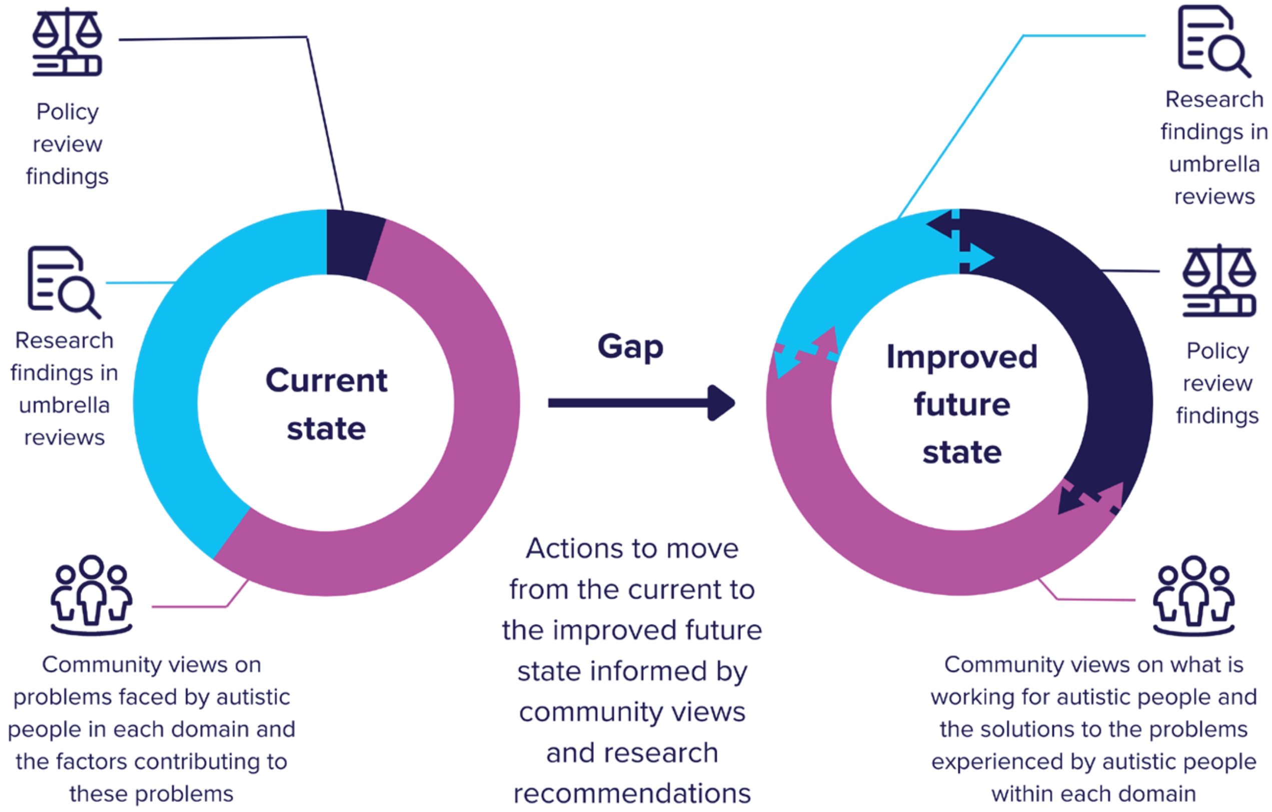
Organisational level	Organisation name	Policy name	Policy date	Reference to autism	Reference to disability	Relevant information
Federal	Autism CRC	A National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia	2018	✓	✓	Guiding principles to be considered during assessment and diagnosis of autism • Evidence based • Individual and family centred • Holistic framework • Strengths focused • Equity • Lifespan perspective Assessment process • Includes a comprehensive needs assessment (medical evaluation and assessment of functioning) and diagnostic evaluation • Diagnostic evaluation can include a ‘tiered’ approach to assessment, where a single clinician may make a diagnosis in specific circumstances, otherwise at least two clinicians must reach a consensus decision. Important considerations • Age • Intellectual and/or communication capacity • Gender • Culturally and linguistically diverse backgrounds • Regional or remote location • Complex psychosocial factors • Differential diagnosis and co-occurring conditions

Organisational level	Organisation name	Policy name	Policy date	Reference to autism	Reference to disability	Relevant information
Federal	Autism CRC	A National Guideline for the Assessment and Diagnosis of Autism in Australia (Draft updated guideline for public consultation)	2023	✓	✓	Guiding principles to be considered during assessment and diagnosis of autism: • Client and family centred • Strengths focused • Holistic • Helpful • Evidence-based • Culturally sensitive • Respecting First Nations Peoples • Neurodiversity-affirming • Competent • Equity • Coordinated Assessment process: • Includes a referral, comprehensive needs assessment (medical evaluation and assessment of functioning), and diagnostic evaluation, with referral for supports made at any stage as a need is identified • A tiered approach should be adopted, commencing with a lead practitioner, and including a consensus team diagnostic evaluation if high diagnostic confidence cannot be achieved • The comprehensive needs assessment and diagnostic evaluation should be conducted by suitably qualified and experienced health professionals in the setting(s) more appropriate to gathering a complete and accurate picture of the client, which supports their privacy, safety, and comfort (telehealth may be used as a complement to in-person sessions).

3.1.4 Community views, research evidence, and policy/guideline gap analysis

As well as the research gaps identified as part of the research landscape mapping, the gap analysis (see Figure 2 for process) allows comparison of the current state (predominantly based upon the community views analysis but also some findings of the umbrella review and policy review) to an improved future state (based upon community views around what is working well, policy review, and some umbrella review findings).

Figure 2: Gap analysis: Current to improved future state



The gap analysis work for the diagnosis section highlighted the following elements that need to be addressed in order reduce the problems experienced by autistic people in relation to diagnosis:

3.1.4.1 There needs to be an increase in the number of appropriately qualified health professionals able to complete autism assessment

Current state

The **community** views survey highlights that there is a lack of appropriately trained health professionals able to provide an autism diagnosis. Access to diagnosticians is even more difficult in remote areas. This lack of diagnosticians has also led to extremely lengthy wait times, delaying autism diagnoses and access to services. This has been compounded by the increasing demand on existing diagnostic services. The **research** landscape mapping results also noted the long wait times for autism assessments as a significant barrier to accessing autism diagnoses. Limited information is included in the literature to explain the underlying causes of long wait times, and presumably these differ depending on geographical, policy, and economic contexts.

Improved future state

The **community** views survey highlights that there must be an increase in the diagnostician workforce, facilitated by increased availability of training for health professionals. Additionally, the community noted that broadening the scope of which professions can provide a diagnosis may be one strategy to increase the number of diagnosticians and reduce waitlists. The National Guideline for the Assessment and Diagnosis of Autism (2023) included in the **policy** review recommends a tiered assessment approach, where cases with high diagnostic confidence only need to be evaluated by one health professional, rather than through a multidisciplinary team. The **research** landscape mapping results present telehealth as a potential strategy for addressing access to diagnostic services; however, the policy review notes that telehealth is not recommended as the sole method by which to conduct a diagnostic assessment for autism.

Steps that can be taken to move from the current to the improved future state include:

- Remove financial and logistical barriers to further training for health professionals who are interested in assessment and diagnosis of autism
- Increase health profession (including paediatrician and psychiatrist) training cohort sizes and publicly funded positions
- Streamline the process for accessing an autism assessment to ensure only the necessary number of health professionals must be involved (as outlined in the National Guideline for the Assessment and Diagnosis of Autism)
- Further exploration of the utility of telehealth as a strategy to provide more diagnostic services to rural and remote areas.

3.1.4.2 There needs to be a reduction in financial barriers to accessing an autism assessment

Current state

The **community** views survey highlights that there are significant costs associated with obtaining an autism assessment, and that cost is a significant barrier to those seeking a diagnosis. Cost was described as particularly impactful when a diagnosis was sought through the private system. Responses noted that there was little to no government-provided financial support or rebates associated with obtaining an autism assessment. It is also possible that the limited number of available diagnosticians has increased the price of private assessments. The **research** landscape mapping results do not mention financial factors related to diagnosis; however, this may be due to the specific scope of the review.

Improved future state

The **community** views survey highlights the need for publicly funded diagnostic services, either through public health pathways or Medicare rebates for privately sought assessments. The National Guideline for the Assessment and Diagnosis of Autism included in the **policy** review notes that service providers should aim to reduce their costs wherever practicable, such as by limiting travel and streamlining appointments. The 2018 Guideline also recommends a review of public funding mechanisms for neurodevelopmental assessments (including autism assessments).

Steps that can be taken to move from the current to the improved future state include:

- Increase the availability of publicly funded autism diagnostic services
- Increase government subsidies for the cost of all stages of an autism assessment, including referral, comprehensive needs assessment, and diagnostic assessment.

3.1.4.3 There needs to be a greater understanding about autism in all its presentations by health professionals and the community

Current state

The **community** views survey highlights that health professionals lack knowledge about autism, some having outdated views or understandings. Community views report that this limited knowledge, particularly in “gatekeepers” to diagnosis, leads to no or delayed referrals where one would have been warranted. The views also discussed a limited knowledge of health professionals (including those making diagnostic assessments) about “nuances” of autism, including its presentation in women and girls, non-cis-gendered people, people with multiple conditions, and those from culturally and linguistically diverse backgrounds. The community views also noted that there was a lack of awareness and understanding about autism in the general community, which was contributing to barriers to accessing autism assessments. The **research** landscape mapping results note that diagnoses are complicated by the range of different presentations of autism, and that there are additional barriers to diagnosis for some populations, such as women and girls. The literature also notes that health professionals require knowledge about the range of autism presentations to provide accurate diagnoses.

Improved future state

The **community** views survey highlights the need for training for health professionals, updating their knowledge about autism and its many presentations and increasing the awareness and understanding of autism in the community. Community views reported that health professionals (including gatekeepers) who were knowledgeable and well informed with up-to-date knowledge about autism support positive diagnostic experiences and provide good quality assessments. The National Guideline for the Assessment and Diagnosis of Autism (2023) as part of the **policy** review notes that health professionals should have up-to-date knowledge and training about autism (including its different presentations), and that different factors that may influence the presentation of autism should be considered during the diagnostic assessment.

Steps that can be taken to move from the current to the improved future state include:

- Co-creation, with the autistic community, of evidence-based training about autism and its presentations for members of the community, health professionals, and diagnosticians

- Further research, co-designed with autistic researchers, to understand the varied ways in which autism presents, to continue to update the knowledge shared with diagnosticians.
- Establishment of specialised diagnostic teams to evaluate individuals who may have fewer common presentations of autism.

3.1.4.4 There needs to be a more neurodiversity affirming approach and understanding of autism

Current state

The **community** views survey highlighted that current diagnostic manuals, guidelines, and resources are outdated and deficit based. In the National Guideline for the Assessment and Diagnosis of Autism (2023) document in the **policy** review, the inclusion of the assessment of functioning within the comprehensive needs assessment is designed to gain a comprehensive picture of a person's strengths, challenges, and support needs, seeing the person holistically rather than only in terms of their "symptoms". The **research** landscape mapping results do not explicitly discuss neurodiversity affirming or non-deficit based approaches; however, some literature notes the need to be supportive and sensitive during the diagnostic process.

Improved future state

The **community** views survey highlighted the need for updated, neurodiversity affirming diagnostic criteria, co-designed with autistic people. They also noted that criteria for adults should also be developed or updated. The community views also described how valuable having neurodiversity affirming and neurodivergent health professionals was during the diagnostic process. Updates made to the National Guideline for the Assessment and Diagnosis of Autism (2023) document in the policy review include those to ensure a more neurodiversity affirming approach, including having "neurodiversity affirming" as a guiding principle. It also provides several recommendations to focus on the individual's strengths and to take a holistic view of the person being assessed throughout the diagnostic process.

Steps that can be taken to move from the current to the improved future state include:

- Updating diagnostic criteria to be neurodiversity affirming, with input from autistic people
- Co-producing, with the autistic community, training and resources to promote neurodiversity affirming practices and attitudes for health professionals
- Support to implement the neurodiversity affirming recommendations outlined in the updated diagnostic guideline.

3.1.4.5 There needs to be implementation of a clear, consistent, and equitable approach to autism assessments

Current state

The National Guideline for the Assessment and Diagnosis of Autism (2018) document included in the policy review has been in place since 2018, with a range of implementation resources provided. However, the **community** views survey highlighted that the diagnostic pathway is lengthy, unclear, and inconsistent. It was noted that there is a lack of a unified, standardised, and collaborative approach causing confusion about when, how, or why to utilise diagnostic services. They report that health professionals are not following the best practice outlined in the policy document, resulting in miscommunication and misinformation. The **research** landscape mapping results identified that facilitators to a high-quality diagnostic process included clear referral processes and the use of multidisciplinary teams.

Improved future state

The **community** views survey identified the need for diagnosticians and providers to offer clear, evidence-based, and uniform diagnoses by implementing the guidelines outlined in the National Guideline for the Assessment and Diagnosis of Autism (2023) document in the **policy** review. The benefit of diagnoses being delivered by multidisciplinary teams was also noted.

Steps that can be taken to move from the current to the improved future state include:

Development of resources to facilitate the implementation of the national guidelines outlined in the National Guideline for the Assessment and Diagnosis of Autism (2023) document in clinical practice across all contexts

- Providing funding (e.g., Medicare rebates) to enable providers to implement all recommendations of the national guidelines and provide high-quality, consistent diagnostic services
- Streamline pathways from referral to service to ensure access, consistency, and clarity regarding processes and pathways for individuals and families
- Ongoing funding to implement and revise the National Guideline for the Assessment and Diagnosis of Autism, to allow it to respond to changes in knowledge and policy context over time.

3.2 Early intervention and support

3.2.1 The "1000 Insights" community views survey

A total of 350 respondents answered at least one of the questions on early intervention and support. This included 115 autistic people and 238 family members or carers of autistic people. The 10 most frequently reported responses are reported within this section. On occasions when there were multiple responses with the same frequency in the tenth position, the total number of responses reported will be greater than 10 to ensure all categories with equal frequencies in the tenth position are represented.

The tables for each question describe the response categories (with example participant responses) in order from the most frequently reported to the least frequently reported. For each category, percentages are provided to indicate the proportion of a respondent group whose response reflected the specific category. These groups are: (a) the entire sample (i.e., everyone), (b) autistic people, (c) family members/caregivers of autistic people, and (d) all respondents who are not represented in one of the groups.

3.2.1.1 Problems experienced by autistic people in relation to early intervention and support services

A total of 350 respondents opted to answer this question on early intervention or support services. This included 115 autistic people and 238 family members or carers of autistic people. The problems experienced were coded into 16 categories, which fall under the following broad areas:

- Difficulty accessing trained and neurodiversity affirming services and health professionals providing early intervention and support, leading to long wait times
- High costs associated with accessing services
- Lack of good quality support and therapy options
- General lack of understanding and awareness about autism leading to late detection and diagnosis of autism
- Access to accurate information about the available services and the choice of picking the intervention
- NDIS process is complex to navigate, and their staff are not knowledgeable about the needs of autistic people.

Table 8 ranks the 10 problems that autistic people experience in relation to the early intervention service (based on the survey responses). The data are ranked from most frequently reported to least frequently reported problems across all respondents. The right-hand columns report the proportion of specific respondent groups that identified this as a problem. Note that respondents often identified within multiple groups (e.g., autistic and a parent/caregiver of an autistic child), so the number of respondents in subgroups exceeds the total number of all respondents.

Of note is that these data show that approximately:

1 in 3 respondents highlighted that there is a long waitlist to access early intervention services.

1 in 5 respondents expressed there is a lack of early intervention services and trained staff.

Table 8: 10 most frequently reported problems experienced by autistic people and their family/carers in relation to early intervention and support services

Rank	Problems experienced by autistic people and their family/carers in relation to early intervention and support services, and sample quotes from responses	Direct insight	% who stated this as a problem			
			All respondents *N* = 350	Autistic people n = 115	Family member/ caregiver of autistic person n = 238	Other n = 178
1	**Waitlists for accessing early intervention are too long** (e.g., the waitlists for allied health services/ professionals are exceptionally long. Due to long wait times diagnoses and interventions are delayed)	*"The waitlist is over 12 months by this time the kids could have had really bad damaging experiences that will impact their life rather than the support they need when they need it."* (ID 234)	34%	25%	37%	35%
2	**Limited availability of early intervention services and trained staff** (e.g., there is a lack of trained staff that can work effectively with autistic individuals; trained staff and interventions are especially difficult to access for people living outside the metro areas such as rural and remote areas)	*"There is a distinct lack of intensive therapy services available. Access to early intervention should be a right for autistic children - not a privilege."* (ID 84)	18%	15%	18%	17%
3	**Finding information about the available services is a challenge** (e.g., it is difficult to find out what services are needed and what is available; it is difficult to know where to find the right information)	*"Lack of knowledge of where these are in the community. How to access these services around work/ family/life commitments."* (ID 1035)	16%	21%	16%	20%
4=	**Cost for accessing services and assessments is expensive** (e.g., therapy and assessment are expensive)	*"Cost of services and time required to support individuals in a society which does not allow parents/ carers to do this whilst maintaining their own self-care makes it extremely difficult. ."* (ID 1222)	14%	18%	10%	15%

Rank	Problems experienced by autistic people and their family/carers in relation to early intervention and support services, and sample quotes from responses	Direct insight	% who stated this as a problem			
			All respondents *N* = 350	Autistic people n = 115	Family member/ caregiver of autistic person n = 238	Other n = 178
4=	**Difficulty accessing support services** (e.g., not knowing how to find services, what is available, or how to access support services; the system can be confusing and difficult to navigate; not being able to get to appointments)	*"The system is very confusing to navigate and often requires a high level of self-advocacy skills."* (ID 995)	14%	18%	10%	15%
6=	**General lack of understanding autism** (e.g., lack of understanding autism in girls/women; masking is commonly misunderstood)	*"Some support services promote masking, teaching autistic children they are 'broken' and needing to change to be accepted. My 10-year-old autistic child was brought to tears in multiple OT appointments because they kept trying to force her to recognise emotions that did not make sense to her."* (ID 976)	12%	23%	12%	12%
6=	**Having choice of therapy options that are based on the individuals' needs** (e.g., there need to be different types of therapy that cater to the individuals' and the family's needs such as individualised, at home, sensory aware, family centred, alternative therapies, strength based)	*"Knowing which support to prioritise and what the cost/benefit is of different therapies. Knowing if you're avoiding ableist therapies that seek to change autistic people."* (ID 376)	12%	28%	10%	11%
8=	**Not accessing early intervention because autism diagnosis has not been confirmed** (e.g., if the child has not yet been diagnosed it is very difficult to access early intervention services)	*"But from experience, paed[diatrician]s and psych[ologist]s are unwilling to provide official diagnoses until children reach school-age, and by then the window of opportunity for early intervention has passed."* (ID 162)	10%	19%	10%	7%

Rank	Problems experienced by autistic people and their family/carers in relation to early intervention and support services, and sample quotes from responses	Direct insight	% who stated this as a problem			
			All respondents *N* = 350	Autistic people n = 115	Family member/ caregiver of autistic person n = 238	Other n = 178
8=	**Lack of support for families** (e.g., there is not enough evidence-based information for families; the support available is not tailored enough, e.g., often overlooks siblings)	*“Not enough support for the family of the autistic person - ie little information, no pathways to finding information”* (ID 242)	10%	12%	11%	10%
10	**Difficult to find or lack of quality good therapists/ therapy/staff** (e.g., it is a challenge to find good quality services and therapists; difficult to know how to find the right people; difficult to know whether the therapy is good)	*“Providers who do not work in best practice approach e.g. not working in natural settings, limited focus on parent engagement or capacity building, emphasis on weekly sessions being only option offered or only chance of 'success' in meeting therapy goals, seeing change etc.”* (ID 1070)	9%	5%	9%	8%

Note. *all other groups that have not been identified separately

3.2.1.2 Factors causing the problems experienced by autistic people in relation to early intervention and support services

A total of 351 respondents opted to answer this question on early intervention. This included 121 autistic people and 170 family members or carers of autistic people. The factors that respondents felt were causing or leading to the problems experienced by autistic people with early intervention and support services were coded into 12 categories, falling under six broad areas:

- Lack of staff trained in delivering early intervention
- Limited available financial support
- NDIS restrictions and unknowledgeable staff
- Community's lack of awareness of autism
- Lack of access to early intervention and support services for families
- Lack of coordination between government agencies and the complexity of the diagnosis pathway.

Table 9 ranks the ten most commonly reported factors that respondents felt were causing the problems that autistic people experience in relation to early intervention and support services reported above. The data are ranked from most frequently reported to least frequently reported problems across all respondents. The right-hand columns report the proportion of specific respondent groups that identified this as a problem.

Importantly, these data show that approximately:

1 in 5 respondents stated that the problems were due to limited access to early intervention services and supports, and trained staff who could deliver them.

1 in 5 respondents highlighted that the problems were due to lack of funding and financial support for accessing early intervention services and supports

Table 9: 10 most frequently reported factors causing the problems experienced by autistic people and their family/carers in relation to early intervention and support services

Rank	Factors causing the problems experienced by autistic people and their family/carers in relation to early intervention and support services, and sample quotes from responses	Direct insight	% who stated this as a problem			
			All respondents *N* = 351	Autistic people n = 121	Family member/caregiver of autistic person n = 170	Other n = 136
1	**Lack of specialist services and trained professionals who can provide early intervention and supports** (e.g., lack of trained staff to deliver neurodiversity affirming services; lack of training for staff)	*"Practitioners using non-supported practices"* (ID 170) *"Shortage of early intervention professionals (e.g., speech pathologists, occupational therapists)."* (ID 319)	22%	17%	35%	32%
2	**Limited funding and financial support opportunities** (e.g., not enough funding for appropriate (early intervention) services and support for carers and the individual; lack of federal and state funding)	*"Funding, and an unwillingness to support these services."* (ID 1394)	11%	12%	17%	15%
3	**Untrained NDIS staff who have limited understanding of the needs of autistic people** (e.g., NDIS workers and planners are often not trained in autism and therefore do not understand the needs of the individual and their family)	*"Lack of willingness or understanding from the NDIS around how support workers can assist in capacity building children."* (ID 266) *"NDIS planners are not equipped to understand or interpret allied health reports and recommendations accurately."* (ID 998)	10%	6%	14%	13%
4=	**Restrictions posed by NDIS on the services families can access and their costs** (e.g., NDIS limits on therapy funding means that not all needs are addressed)	*"Limited NDIS funding that often does not match the supports required."* (ID 317)	9%	7%	12%	14%

Rank	Factors causing the problems experienced by autistic people and their family/carers in relation to early intervention and support services, and sample quotes from responses	Direct insight	% who stated this as a problem			
			All respondents *N* = 351	Autistic people n = 121	Family member/ caregiver of autistic person n = 170	Other n = 136
4=	**Gatekeepers and educators' lack of understanding of autism and services they can access** (e.g., more education about autism is needed for educators, gatekeepers, and health professionals)	*"Teachers are afraid to use the word Autism when approaching parents, teachers are not able to diagnose & do not receive training in what to look out for. They often think children are just naughty or disruptive."* (ID 149)	9%	14%	14%	13%
6=	**The early intervention services are expensive** (e.g., services are overpriced, and everyone charges the maximum amount; not everyone can afford the services)	*"Poverty - families with autistic children tend to be financially challenged."* (ID 935)	7%	5%	10%	14%
6=	**Community's lack of awareness and understanding of autism** (e.g., there is a lack of education in the community which leads to a lack of awareness and understanding of autism in the community)	*"Lack of understanding and knowledge about the differences in autistic people"* (ID 976) *"Parents who want someone to 'fix' their child and not understand they can learn strategies to support their child's development and ability to participate in the community."* (ID 753)	7%	7%	10%	10%
8=	**Lack of support and education for families** (e.g., not enough supports and tools for families to support their children and themselves)	*"Without supporting the family, the neurodivergent person's world collapses. Families are often undiagnosed neurodivergents themselves and are not receiving support. Siblings are often also affected and do not get support."* (ID 180)	6%	5%	6%	9%

Rank	Factors causing the problems experienced by autistic people and their family/carers in relation to early intervention and support services, and sample quotes from responses	Direct insight	% who stated this as a problem			
			All respondents *N* = 351	Autistic people n = 121	Family member/ caregiver of autistic person n = 170	Other n = 136
8=	**Access to information or resources available to families** (e.g., families are not sure where to find the right information; lack of centralised information, which can make it difficult and overwhelming for parents to access information)	*"I think parent education (if diagnosing for a child) is key and there are many organisations that can facilitate this, some of which are autistic led (and for myself and my son, the most worthwhile and effective)."* (ID 190)	6%	7%	9%	7%
8=	**Access to early intervention service and support** (e.g., there are several barriers to access early intervention services and support, such as funding, and time to access the services; not enough allied health services to meet the high early intervention service demand)	*"For those with not complex needs, a lack of short term and generalized early intervention supports within the community or at mainstream day-care and prep."* (ID 994)	8%	7%	8%	8%

Note. *all other groups that have not been identified separately

3.2.1.3 Factors that could prevent or reduce the problems experienced by autistic people in relation to early intervention and support services

A total of 190 respondents opted to answer this question on early intervention and support services. This included 57 autistic people and 132 family members or carers of autistic people. The factors that respondents identified as preventing or reducing the problems experienced by autistic people with early intervention and support services were coded into 21 categories. These categories fall under the following nine broad areas:

- More funding or financial support
- Better access to early intervention service providers and health professionals who are either neurodivergent or neurodiversity affirming
- More therapy options that are individualised
- More support for families
- More training and education about autism
- Listen to autistic perspectives
- Training NDIS staff about autism and support for families navigating the NDIS system
- More collaborative work between health professionals and updating their knowledge of autism
- More acceptance and awareness of autism.

Table 10 ranks the ten most commonly reported factors that respondents reported could prevent or reduce the problems that autistic people experience in relation to accessing early intervention and support services reported above. The data are ranked from most frequently reported to least frequently reported problems across all respondents. The right-hand columns report the proportion of specific respondent groups that identified this as a problem.

Importantly, these data show that approximately:

1 in 5 respondents stated that access to more funding and financial support could prevent or reduce the problems experienced by families or autistic people in relation to early intervention and supports

Almost 1 in 5 respondents identified that access to more therapy services, especially in remote places could prevent or reduce the problems experienced by families and autistic people in relation to early intervention and supports.

Table 10: 10 most frequently reported factors that could prevent or reduce problems experienced by autistic people and their family/carers in relation to early intervention and support services

Rank	Factors that could prevent or reduce the problems experienced by autistic people and their family/ carers in relation to early intervention and support services, and sample quotes from responses	Direct insight	% who stated this as a problem			
			All respondents *N* = 190	Autistic people n = 57	Family member/ caregiver of autistic person n = 132	Other respondent groups* n = 103
1	**More funding and financial support** (e.g., increased and better funding is needed to support families to access appropriate services; more funding for research is needed)	*"More funding to encourage more access and more quality supports in service delivery."* (ID 616)	22%	18%	21%	23%
2	**Access to more early intervention providers and programs** (e.g., increase availability of early intervention providers, especially in regional areas)	*"Work with professional registration bodies to identify strategies to increase capacity to provide early intervention services."* (ID 317)	17%	14%	19%	14%
3	**Access to more autistic or neurodiversity affirming health professionals** (e.g., more training and education for health professionals on how to provide neurodiversity affirming services)	*"Neuro-affirming OT support that doesn't aim to change or fix autistic children. Instead provide them with the tools to navigate the neurotypical world."* (ID 976)	16%	25%	19%	17%
4	**Government investment in training more health professionals for delivering early intervention and supports** (e.g., more government investment to support professional development, training, and university courses to train more health professionals)	*"Funding free courses for [service provider's name] to deliver training to schools and childcare."* (ID 408)	15%	7%	14%	16%

Rank	Factors that could prevent or reduce the problems experienced by autistic people and their family/carers in relation to early intervention and support services, and sample quotes from responses	Direct insight	% who stated this as a problem			
			All respondents *N* = 190	**Autistic people** n = 57	**Family member/caregiver of autistic person** n = 132	**Other respondent groups*** n = 103
5	**Provide individualised therapy options for families** (e.g., more therapy options would help to address the individual's and family needs)	*"An understanding that every child is different and has different needs."* (ID 1021) *"Letting the autistic person lead their own learning if possible - help them with what they decide they want to work on and learn about."* (ID 1320)	13%	14%	12%	13%
6=	**More support for families** (e.g., more education for families (parents, children, and their siblings) to help them to access the services and systems)	*"Better support for families with autistic children. I don't think the bonus payment for carers has gone up in a decade. What would buy supports or novel interventions a decade ago doesn't go that far these days." (935)*	12%	5%	10%	13%
6=	**Access to early intervention and support without a confirmed diagnosis** (e.g., access to early intervention and supports provided during/prior to assessment to provide early interventions and supports to all autistic individuals)	*"Allow access to early intervention services during the assessment phase and not only after the diagnosis is formalised.!"* (ID 426)	12%	11%	12%	16%
8	**Need more support in schools or early childhood education settings** (e.g., more staff)	*"Increased early intervention facilities through Education."* (ID 666)	10%	16%	9%	10%
9=	**Access to NDIS funding** (e.g., improved policies and procedures supporting access to NDIS funding; more funding for early intervention services and supports)	*"More funding for permanent and for visiting specialists and allied health outside the major cities."* (ID 992)	9%	7%	11%	11%

Rank	Factors that could prevent or reduce the problems experienced by autistic people and their family/carers in relation to early intervention and support services, and sample quotes from responses	Direct insight	% who stated this as a problem			
			All respondents *N* = 190	Autistic people n = 57	Family member/caregiver of autistic person n = 132	Other respondent groups* n = 103
9=	**Improve understanding and awareness around autism** (e.g., more training and education for professionals and the community)	*"Train professionals to value being autistic and not to presume autistic people want to be neurotypical or want to learn how to cope with unreasonable neurotypical demands and environments."* (ID 151)	9%	14%	10%	9%

Note. *all other groups that have not been identified separately

3.2.1.4 Factors that are working well, or have worked well, for autistic people in relation to early intervention and support services

Only 138 respondents (39%) replied to this question. This included 43 autistic people and 94 family members or carers of autistic people. From these responses, the factors that, when available, are reported to be working well, or have worked well, for autistic people in relation to early intervention and support services were coded into 19 categories, which fall under the following broad areas:

- Access to funding or financial support
- Good collaboration amongst health professionals
- Individualised therapy options
- Access to allied health professionals such as OTs for required assessments and interventions
- Supporting families and organisations delivering early intervention
- Families accessing online resources or support groups
- Education system and the wider community's awareness of autism
- Nothing has worked, do not know.

Table 11 ranks the ten most commonly reported factors that respondents indicated to be working well, or have worked well, for autistic people in relation to early intervention and supports. The data are ranked from most frequently reported to least frequently reported factors that are working well across all respondents. The right-hand columns report what proportion of specific respondent groups reported this as a factor that is, or has, worked well.

Importantly, these data show that approximately:

1 in 5 respondents expressed that when families have access to funding and financial support, early intervention and supports work well for families and autistic people.

1 in 5 respondents stated that when there is good and clear communication between health professionals and families, early intervention and supports work well for families and autistic people.

Table 11: 10 most frequently reported factors that are working well, or have worked well, in relation to autistic people and their family/carers accessing early intervention and support services

Rank	What is working well, or has worked well, in relation to autistic people and their family/carers accessing early intervention and support services, and sample quotes from responses	Direct insight	% who stated this as a problem			
			All respon-dents *N* = 138	Autistic people n = 43	Family member/ caregiver of autistic person n = 94	Other respondent groups* n = 73
1	**Financial support and funding through NDIS** (e.g., where the funding is appropriate/sufficient; access to a range of supports)	*"NDIS funding is good, so long as it is flexible and can be used for a variety of therapies."* (ID 90)	21%	16%	21%	19%
2	**Having access to early intervention and support services as early as possible** (e.g., once the access to early intervention services is granted, the services work well, especially if accessed early on)	*"Early Intervention/access to specialised setting to set them up for success before accessing mainstream schools."* (ID 284) *"Once access is finally granted and funded it works amazingly well for the patient."* (ID 1293)	20%	19%	19%	15%
3	**Enabling families to choose from available therapy options** (e.g., specialised services, therapy in real life scenarios, family and person-centred therapy)	*"For people who are self and planned managed, many are choosing to redirect funds from other therapies towards ensuring access to music therapy. This design feature in the NDIS is thus enabling choice and control for people with disability, as it should."* (ID 916)	14%	12%	11%	16%
4	**Evidence-based practice and using evidence from research** (e.g., more autistic co-designed research; research that clarifies misinformation; research on the effectiveness of early intervention)	*"Research unequivocally demonstrating that early intervention not only facilitates notable developmental progress for autistic children, but also yields impressive returns on investment. The research substantiates the life-changing impact early intervention services can have on autistic children."* (ID 1556)	13%	21%	11%	16%

Rank	What is working well, or has worked well, in relation to autistic people and their family/carers accessing early intervention and support services, and sample quotes from responses	Direct insight	% who stated this as a problem			
			All respon-dents *N* = 138	Autistic people n = 43	Family member/ caregiver of autistic person n = 94	Other respondent groups* n = 73
5=	**Choice of intervention and supports through NDIS support** (e.g., families being able to choose the type of intervention like music, art)	*"Access to NDIS and therapy services. Early Intervention/access to specialised setting to set them up for success before accessing mainstream schools."* (ID 284)	9%	12%	10%	8%
5=	**Utilising the expertise of allied health professionals** (e.g., health professionals with expertise in autism and who are neurodivergent and can deliver neurodiversity affirming services)	*"The thorough use of speech therapists, paediatricians and psychologists to give a thorough assessment so the proper supports can be accessed."* (ID 596)	9%	23%	10%	4%
5=	**Individualised therapy choices** (e.g., therapy that is individualised, regular, consistent, and family and person-centred)	*"Allied health professionals who understand the need to travel to a child's preferred environment, to increase the level of engagement and so provide value for money for the therapy and better outcomes for the child."* (ID 831)	9%	2%	10%	11%
5=	**Choice of early intervention and supports available to all families** (e.g., having different options of early interventions and supports available, such as Telehealth)	*"Early intervention flexibility, when a parent can receive NDIS support to access private providers."* (ID 1011)	9%	7%	6%	14%

Rank	What is working well, or has worked well, in relation to autistic people and their family/carers accessing early intervention and support services, and sample quotes from responses	Direct insight	% who stated this as a problem			
			All respon-dents *N* = 138	Autistic people n = 43	Family member/ caregiver of autistic person n = 94	Other respondent groups* n = 73
5=	**Support families to navigate the system and self-advocate** (e.g., being given opportunities to communicate and share experiences with other parents; support groups, carer support services, early childhood development programs and respite care work well for families)	*"We used [service provider's name] early intervention partner. I found them very good. They didn't find the services for us, but they set us on the right track."* (ID 1251)	9%	12%	7%	11%
5=	**Support for parents, siblings, family, including respite and specialist playgroups**	*"Carer support services and respite care makes more difference than weekly individual therapy (respite is rarely available for young children under age 7 and it should be for some families)"* (ID 1055)	9%			
10	**Early intervention services that have an impact on the child's development** (e.g., early intervention services can provide an autistic child and their family with the right tools, knowledge, and support; early education, autism services, services providing autism information sessions, and general support services are reported to work well)	*"[A service's name] a service run by [organisation's name] that employs and is informed by Autistic people is an excellent organisation with clearly accessible and relevant information for everyone about autism (everything you want to know)."* (ID 287)	5%	3%	7%	6%

3.2.2 Umbrella review: Early intervention and support services

The focus of this review was on early intervention approaches for children on the autism spectrum. It is based on the findings from the umbrella review conducted by Trembath et al. (2022). The terms used for the searches, and the number of articles identified, screened, and included, are provided in Appendix D-1 and Appendix D-2. The final umbrella review reports on 58 systematic reviews, five of which were led by Australian authors. Thirty-three reviews were published between 2018 and 2020, and 25 were published between 2010 and 2017.

The information and findings from the included reviews are summarised in the subsections below. When reporting on the number of people or participants in the review, this will be represented as *n* = [number of participants]. When reporting on the number of reviews that considered a topic, this will be represented as *k* = [number of reviews].

3.2.2.1 Participants within included reviews

Of the 58 systematic reviews included, 53 provided details about the total number of participants. In all, there were 41,375 participants, with the sample sizes of individual studies ranging from 66 to 6,240 participants. Forty-four systematic reviews indicated the age range of participants, which spanned from 4 months old to 65 years old. Within these studies, 81% (*n* = 11,218 of *n* = 13,482) were identified as male and 17% (*n* = 2,264) as female.

3.2.2.2 Quality of included reviews

The quality of the included systematic reviews was assessed using the Critical Appraisal Checklist for Systematic Reviews and Research Syntheses (CACSRRS) tool that assesses the methodological quality of a systematic review. The maximum score is 11, which indicates a very "high quality" systematic review. Systematic reviews including meta-analyses were scored between 6 and 11 (mode = 10), while systematic reviews with only a narrative review of the literature scored between 4 and 9 (mode = 7). Four systematic reviews scored the maximum points, 27 received a high summary rating, and 31 received a low summary rating.

3.2.2.3 Topics of included reviews

All 58 systematic reviews reported data on the effect of early intervention approaches on children on the autism spectrum. However, there were 34 practice/category-focused systematic reviews that organised findings into nine intervention areas. These were behavioural interventions (*k* = 8), developmental interventions (*k* = 5), naturalistic developmental behavioural interventions (NDBIs) (*k* = 7), sensory-based interventions (*k* = 9), Treatment and Education of Autistic and related Communications Handicapped Children (TEACCH) (*k* = 2), technology-based interventions (*k* = 11), animal-assisted interventions (*k* = 7), cognitive behavioural therapy (CBT) (*k* = 4), and other interventions (*k* = 2). The interventions were grouped and presented according to the following topic areas discussed in table 11: (a) intervention effect on child outcomes, (b) intervention effects on family outcomes, (c) influence of delivery characteristics, and (d) influence of child characteristics.

3.2.2.4 Research gaps

The umbrella review identified a number of research gaps, which are summarised in Table 12. In brief, current literature is largely inconclusive about the effectiveness of various categories of early intervention strategies. There is a need for high quality research that considers the impact of delivery method and individual characteristics on outcomes, and that reports on adverse effects from interventions. There is also a need for the development of validated tools that holistically assess intervention or support outcomes for child and family. Likewise, there is an urgent need for research with culturally and linguistically diverse samples that are co-produced, to allow for a more authentic representation of the experience of autistic children and their caregivers and to better guide the development of meaningful interventions.

Table 12: Umbrella review findings for early intervention and supports for autistic children

Topic	Number of reviews on topic; citations	Key findings	Key research gaps identified
Intervention effects on child outcomes	k = 58 See Trembath et al., 2022	• This review found no evidence of a single intervention that works best for all autistic children. No intervention considered in this review effectively targeted all child and family outcomes • Positive effects were found from behavioural interventions in some key areas of child outcomes related to core autism characteristics (e.g., social communication and restrictive and repetitive interests/behaviours), sensory behaviour, communication, receptive and expressive language, cognition, motor skills, play, social-emotional/challenging behaviour, and adaptive behaviours. Positive effects were also noted for school/learning readiness and academic skills • Positive effects were found from naturalistic developmental behavioural interventions (NDBIs) on child outcomes in the areas of social communication, communication, expressive and receptive language, cognition, motor skills, play, and school/learning readiness • Technology-based interventions produced positive child outcomes in the areas of communication, cognition, motor skills, play, adaptive behaviour, school/learning readiness, and academic skills • CBT interventions were also found to impact child outcomes in the areas of social communication, sensory behaviour, cognition, motor skills, play, adaptive behaviour, school/learning readiness, and academic life • Inconsistent or inconclusive effects were noted for sensory-based interventions, except in the subcategories of music therapy, where positive effects were noted in child outcomes in the areas of social communication, communication, cognition, motor skills, social-emotional/challenging behaviour, play, and school/learning readiness • Inconsistent or inconclusive effects were noted for TEACCH and animal-assisted interventions	• Need for more studies that examine effects of interventions on children's education and participation, quality of life, and family well-being • Development of functional and meaningful outcome measures in autism research needed to better inform policy and practice • Insufficient reporting of adverse effects (null or negative effects) in the literature

Topic	Number of reviews on topic; citations	Key findings	Key research gaps identified
Intervention effects on family outcomes	k = 58 See Trembath et al., 2022	• Although caregivers were considered essential partners in intervention delivery, only a few studies reported on the effect of interventions on caregiver outcomes. • Positive effects were noted for caregiver communication and interaction strategies for practices in the categories of developmental interventions and NDBIs. • Positive effects were noted for social and emotional well-being for practices in the categories of NDBIs and sensory-based interventions • There was also positive effect found for practices in the NDBIs for caregiver satisfaction	• Need for more studies that examine the effect of interventions on caregiver outcomes
Influence of delivery characteristics	k = 12 See Trembath et al., 2022	• Inconclusive evidence available about the influence of delivery characteristics on outcomes. As such, reliable inferences cannot be made about the best intervention approach	• Need for more studies that examine the effect of delivery characteristics on outcomes
Influence of child characteristics	k = 9 See Trembath et al., 2022	• Inconclusive evidence available about the influence of child characteristics on outcomes. Consequently, reliable conclusions cannot be made about what type of individual profile is best suited for a particular intervention.	• Need for policies and practices that consider and incorporate individualised approaches to intervention decision-making, within an evidence-based practice framework

3.2.3 Policy and guideline review

The National Guideline for Supporting the Learning, Participation and Wellbeing of Autistic Children and their Families in Australia (2022) is the focus of this policy review. The Guideline speaks to many of the critical areas of gaps identified in the literature that can be addressed in clinical practice (see Table 13).

Table 13: Policy review findings for early intervention and supports for autistic children

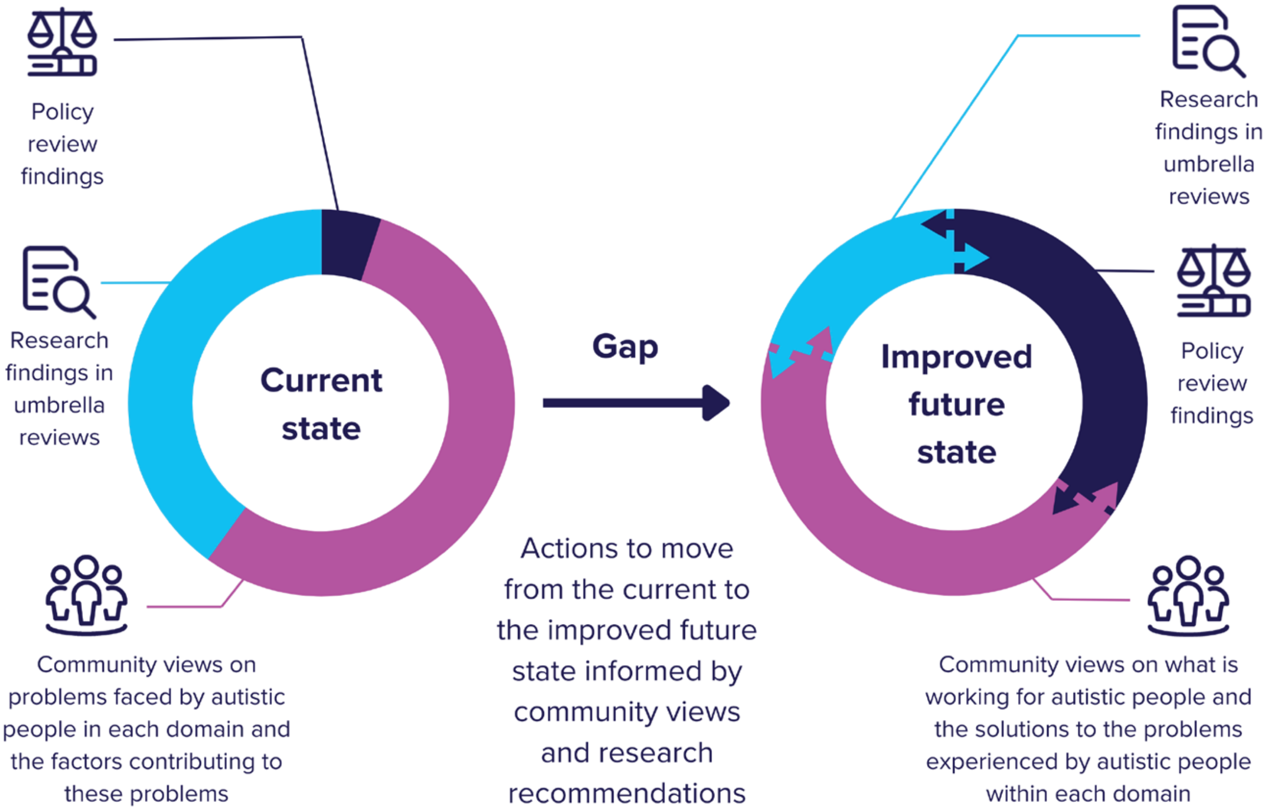
Organisation level	Organisation name	Policy name	Policy date	Reference to autism	Reference to disability	Relevant information
Federal	Autism CRC	The National Guideline for Supporting the Learning, Participation and Wellbeing of Autistic Children and their Families	2022	✓	✓	• Guiding principles for providing support and conducting interventions with children with autism • Child and family-centred • Individualised • Strengths-focused • Evidence-based • Holistic framework • Honour childhood • Lifespan perspective • Ethical • Respect culture • Accessible to Australia’s First Nations People • Consent: Assent and informed consent • Parent and family affirming • Qualified practitioners • Timely and accessible • Coordinated **Intervention Process:** ***Goal setting*** • Child and family led with the support of practitioners and others to set goals that are appropriate, meaningful, and feasible in relation to acquiring and maintaining skills • All goals should be neurodiversity affirming • Goals centre on helping the child gain skills that enhance their participation, learning, and well-being • Practitioners and family work in partnership to set goals that empower the family to support, advocate for their child, and promote child’s participation, learning, and well-being • Unique aspects of the child and family context and experience should be considered when setting goals.

Organisation level	Organisation name	Policy name	Policy date	Reference to autism	Reference to disability	Relevant information
						Interventions/Supports • Centre on helping the child to communicate with different people in everyday contexts by aiding in developing the child's comprehension, as well as considering how and why the child communicates • Support the sensory needs of the child • Help the child develop their cognitive, socio-emotional, motor, and functional movement, academic skills, and skills related to carrying out daily activities • Use evidence-based approaches and share these strategies with the child and family • Ensure that child and family understand rationale for any support or intervention being proposed, along with potential costs, and suggest alternative options where possible • Led by parents or practitioners who are most likely to foster meaningful and sustained increases in child's participation, learning, and well-being • Practitioners who meet the professional requirements in terms of appropriate qualifications, knowledge, skills, and professional experience to their level of responsibility, supervision, and regulation. ***Important considerations*** • Age • Intellectual and/or communication capacity • Gender • Culturally and linguistically diverse backgrounds • Regional or remote location • Complex psychosocial factors • Differential diagnosis and co-occurring conditions

3.2.4 Community views, research evidence, and policy/guideline alignment and gap analysis

As well as the research gaps identified as part of the research landscape mapping, the gap analysis (see Figure 3 for process) allows comparison of the current state (predominantly based upon the community views analysis but also some findings of the umbrella review and policy review) to an improved future state (based upon community views around what is working well, policy review, and some umbrella review findings).

Figure 3: Gap analysis: Current to improved future state



The early intervention and supports gap analysis outlines steps that can be taken to improve the experiences of autistic people and better meet their needs as they relate to early intervention and supports.

3.2.4.1 There needs to be improved access to early intervention services or support services for autistic children

Current state

The **community** views survey highlighted that the primary concern for parents and families of autistic children related to the lengthy wait time to access early intervention services and supports, which they linked to the lack of trained professionals that can provide early intervention services. The findings from the community views survey indicate that this creates a bottleneck situation resulting in some children waiting months or even years to be seen, by which time the benefits of early intervention may be lost. The problems related to access to early intervention services were not captured in the **research** landscape mapping.

Improved future state

The **community** views survey suggested that having more trained early intervention providers would help to improve the accessibility of early intervention and support services for autistic children. In the National Guideline for Supporting the Learning, Participation and Wellbeing of Autistic Children and their Families (2022) document in the **policy** review the provision of universal accessibility to early intervention services and supports for autistic children is highlighted in several recommendations.

Steps that can be taken to move from the current to the improved future state include:

- Further consultation with key stakeholders (e.g., health practitioners, autism community, autism experts, relevant policymakers) to identify and develop strategies that can expand pathways for early intervention and supports for autistic children in the context of limited human resources
- Provide incentive schemes for practitioners working in early intervention and supports to boost interest in the area for potential practitioners and retain existing ones
- Further consultation and partnership with universities to identify and implement strategies that may build student interest and training in areas of study related to early intervention.

3.2.4.2 Families of autistic children need to be better supported to help them better understand autism and provide optimal care to autistic children

Current state

The **community** views survey pointed out that parents and families of autistic children often lack knowledge and understanding of autism and may be unsure of how to navigate the pathways for early intervention and supports. The community views survey indicated that often it is difficult for parents or families to find clear and correct information about autism and available resources and supports to be able to properly advocate for their autistic children.

Improved future state

The **community** views survey revealed that healthcare providers who were thorough in their assessment and reporting and who communicated clearly worked well for them.

Steps that can be taken to move from the current to the improved future state include:

- Co-development of simple and user-friendly informational guides that build awareness and sensitise parents and families of autistic children (and other supporters) about autism and include pathways to care, steps involved in accessing care, and listing of autism support entities. This can be made accessible through relevant government and non-government bodies and partners (e.g., NDIA, NDIA approved practitioners, autism support entities)
- Educate parents and families of autistic children about the rights of autistic children as well as the policy guidelines related to early intervention to help them to advocate.

3.2.4.3 Early intervention and support services need to be made more affordable for families of autistic children

Current state

The cost of services and inadequacy of funding was highlighted as a high priority concern for parents and families of autistic children in the **community** views survey. The community views survey highlighted that parents and families of autistic children felt that limited funding support available for early intervention and support services was prohibitive in allowing them to access these services for their autistic children. The affordability of early intervention services was not captured in **research** landscape mapping but is identified as a major problem for parents and families of autistic children, especially for those who lack financial stability or who have multiple children with special needs.

Improved future state

The **community** views survey revealed that parents and families of autistic children believed that NDIS funding works well when there is flexibility in how it can be utilised for early intervention services. The availability of affordable early intervention and supports is highlighted as a key component of access in the **policy** the National Guideline for Supporting the Learning, Participation and Wellbeing of Autistic Children and their Families (2022). The NDIS procedural guidelines for early intervention support the community views survey indicating that funding is available for autistic children but indicate that the level of funding support is based on an assessment of need made by NDIS staff.

Steps that can be taken to move from the current to the improved future state include:

- Further consultation with the autistic community about the challenges they experience with accessing government funding support with an aim to (a) revise, simplify, and streamline the processes; and (b) increase government subsidies where warranted
- Work towards increasing the availability of publicly funded early intervention and support services
- Build the capacity of parents and family members of autistic children to better advocate for the funding needs for their autistic children.

3.2.4.4 There needs to be an improvement in the level of autism knowledge and understanding of professionals working in the area of early intervention and supports

Current state

The **community** views survey identified a lack of awareness, knowledge, and understanding of autism that was neurodiversity affirming, as a major problem parents and families of autistic children and autistic children encountered. This problem was experienced across health practitioners, support services, and educators. The community views survey highlighted that this can be a distressing experience for autistic children as well as for parents and family members. The **research** landscape mapping did not capture issues related to autism knowledge and understanding in early intervention. Nevertheless, this was a recurrent problem identified in the community views survey.

Improved future state

The **community** views survey suggested that improving awareness and education that is neurodiversity affirming through research, evidence-based practice, and autism organisations works well in reducing this problem. The National Guideline for Supporting the Learning, Participation and Wellbeing of Autistic Children and their Families (2022) document in the **policy** review indicates that individuals or entities delivering early intervention services for autism have autism-specific training. It outlines that practitioners are to adhere to the guiding principles outlined in the policy in their approach to autistic children.

Steps that can be taken to move from the current to the improved future state include:

- Co-creation (actively involve the autistic community) of evidence-based autism-specific training that is relevant and accessible to professionals involved in early intervention and supports (such as early intervention practitioners, educators, and relevant NDIA staff). This training can be incorporated as components of standard training as well as included in annual professional development training packages and can be mandated or recommended in policy
- Provide and promote avenues for parents and families of autistic children to officially advocate as well as raise concerns about early intervention and support service providers who explicitly violate policy guidelines for early intervention.

3.2.4.5 There needs to be an expansion in the range of therapeutic services and quality of care available to autistic children

Current state

The **community** views survey highlighted that parents and families of autistic children need to be better included in the therapeutic decision-making and intervention process and offered a wider range of therapeutic options. This aligns with the **research** landscape mapping findings which indicated that many different types of therapeutic interventions offer positive outcomes for skill development in autistic children. Parents and families of autistic children also pointed out that they experience challenges accessing quality therapy with neurodiversity affirming therapists. However, there was an absence of research that considered the effects of clinician characteristics on the quality of early intervention care provided to autistic children in the research landscape mapping.

Improved future state

In the **community** views survey, parents and families of autistic children indicated that having flexibility in being able to access alternative therapies (such as music, animal) or therapeutic options that are individualised, consistent, and child and family-centred works well for them. This aligns with the National Guideline for Supporting the Learning, Participation and Wellbeing of Autistic Children and their Families (2022) document in the **policy** review which outlines that early intervention for autistic children should be individualised, child and family centred, parent and child affirming, and neurodiversity affirming.

Steps that can be taken to move from the current to the improved future state include:

- Provide consultation between the autism community and relevant early intervention professionals to assess community needs alongside strength-focused, evidence-based therapies that can be accepted as alternative therapeutic options. Once identified, these therapies can then be considered for approval by the NDIA as funded alternative therapeutic options
- Increase accountability measures (e.g., through more frequent auditing) for early intervention providers approved by the NDIA to improve adherence to policy guidelines related to early intervention
- Currently, research focuses primarily on effectiveness of intervention modalities for children. However, there is a paucity of research that explores the experiences of autistic children and their family members accessing early intervention services, quality of care, and the effect of clinician characteristics on child outcomes. Research in these areas may help to identify additional enablers and barriers to positive outcomes for autistic children as well as informing the development of strategies that can improve early intervention services.

3.3 Education

The community views survey asked about primary, secondary, and post-secondary education within the one domain. However, because the research and policy differ between primary/secondary and post-secondary education, individual research reviews and policy reviews have been conducted for primary/secondary (Sections 4.3.2, 4.3.3) and post-secondary settings (Sections 4.3.5, 4.3.6). The education domain gap analysis, which covers both primary/secondary and post-secondary, is then presented in section 4.3.7.

3.3.1 The "1,000 Insights" community views survey

A total of 866 respondents answered at least one of the questions on education. This included 373 autistic people, 504 family members or carers of autistic people, and 184 education staff. The 10 most frequently reported responses (where applicable) are reported within this section.

The tables for each question describe the response categories (with example participant responses) in order from the most frequently reported to the least frequently reported. For each category, percentages are provided to indicate the proportion of a respondent group whose response reflected the specific category. These groups are: (a) the entire sample (i.e., everyone), (b) autistic people, (c) family members/caregivers of autistic people, (d) education professionals, and (e) all respondents who are not represented in one of these groups.

NB. Whilst the survey informed respondents that education included post-secondary educational settings, the majority of the responses spoke about school, therefore focussing on the primary and secondary setting.

3.3.1.1 Problems experienced by autistic people in relation to education

A total of 866 respondents opted to answer this question on education. This included 373 autistic people and 504 family members or carers of autistic people. The problems experienced were coded into 16 categories, which fall under the following 10 broad areas:

- Lack of autism knowledge or training held by staff working in educational settings
- Physical environment is not supportive of autistic students
- Misalignment between the needs of autistic students and the instruction and assessment provided at school
- Systemic expectations of schools (e.g., rules, routines, attendance requirements) mean that it is hard for schools to be genuinely inclusive for autistic students
- Curriculum is based on neurotypical standards which may not be suitable for (or insufficiently adjusted to) the needs of autistic children
- Social elements of school, including peer relationships and bullying
- Focus on, or misinterpretation of behaviour and the use of behaviourally based strategies
- School has an impact on the mental health and identity of autistic students
- Communication styles and preferences of autistic people are not well-understood

- Lack of patience, empathy, care, or understanding (including ableism, mistreatment, stigma, and discrimination) of autistic students in educational settings.

Table 14 ranks the 10 categories of problems that autistic people experience in relation to education. The data are ranked from most frequently reported to least frequently reported problems across all respondents. The right-hand columns report the proportion of specific respondent groups that identified this as a problem. Note that respondents often identified within multiple groups (e.g., autistic and a parent/caregiver of an autistic child), so the total of the subgroups exceed the total number of all respondents.

Of note is that these data show that approximately:

3 in 10 respondents highlight that the lack of teacher awareness, knowledge, and/or experience in autism (and broader neurodiversity), its heterogeneity, and associated needs impact autistic people's access to education.

1 in 4 respondents report that the environment is not designed for autistic students and/or is not sensory friendly.

Table 14: 10 most frequently reported problems experienced by autistic people in relation to education

Rank	Problems experienced by autistic people in relation to education and sample quotes from responses	Direct insight	Respondents who stated this as a problem				
			All respon-dents *N* = 866	Autistic people n = 373	Family member or caregiver of autistic people n = 504	Education professional n = 184	Other respondent groups* n = 408
1	**A lack of teacher awareness, knowledge, and/or experience in autism (and broader neurodiversity), its heterogeneity, and associated needs** (e.g., teachers do not understand sensory sensitivities or autistic children's communication)	*"School [thinks] they can put supports in place for learning and then remove them every 3 to 6 months as the students 'should be getting better', no understanding of lifelong or that autism can present in a fluctuating manner i.e., can do this week and not next week."* (ID 357) *"I have colleagues who will say their classroom is quiet so a student doesn't need earmuffs, but the student has difficulty with noises like the air conditioner."* (ID 1430)	30%	24%	31%	37%	30%
2	**The school or learning environment is not designed for autistic students and/or is not sensory friendly** (e.g., sensory environment is overwhelming; lack of quiet spaces)	*"It is a difficult thing to learn in an environment that is for example noisy - My son was placed in a class of 50 kids in a <location removed> mega class with [no] physical walls between another three classes of 24 children. School then had the mental gymnastics to state that the classroom was quiet for my autistic child with sensory processing difficulties."* (ID 85) *"Sensory issues in autism are not accommodated so autistic learners 'suffer' from noise, lights and overwhelming sensory inputs that non-autistic individuals may hardly notice."* (ID 482)	28%	32%	27%	28%	30%

Rank	Problems experienced by autistic people in relation to education and sample quotes from responses	Direct insight	Respondents who stated this as a problem				
			All respondents *N* = 866	Autistic people n = 373	Family member or caregiver of autistic people n = 504	Education professional n = 184	Other respondent groups* n = 408
3	**There is a lack of, or inconsistent use of, reasonable accommodation/adjustments** (e.g., accommodations not seen as beneficial for student; unwillingness to make adjustments)	*“Proper understanding on what accommodations can and should be made for the child. There is a lot of autistic children missing out on appropriate accommodations because the teacher feels it is 'unfair' on the neurotypical children.”* (ID 511)	23%	22%	26%	22%	22%
4	**Instructional approaches do not consider the needs of autistic students** (e.g., staff do not adjust learning tasks to meet individual needs; ambiguous language; too much information)	*“For me, the instructions are vague and I have to make a lot of assumptions so if they would just make a little more effort regarding clear and specific instructions; I could complete the work without having to ask questions about what I am supposed to be doing.”* (ID 830) *“The issues I faced were mostly confusion with what was being asked in assignments while at Uni. There were confusing terms like ‘discuss' or 'explore' etc when I needed to write an essay. One thing that really helped me was to see a previous example or template so I knew how to structure my assignments.”* (ID 98)	17%	20%	13%	11%	21%
5	**Pedagogy or assessment methods do not consider autistic cognitive profiles or differences** (e.g., autistic people may learn differently; standardised testing is inappropriate; group work is difficult)	*“Education tends to be a ‘one size fits all’. I for one take information in quite differently to most people.”* (ID 541) *“Being expected to participate in a neurotypical way - I never liked speaking up in class or talking much but my teachers always forced me to and it made me highly uncomfortable.”* (ID 1224)	15%	21%	15%	13%	14%

Rank	Problems experienced by autistic people in relation to education and sample quotes from responses	Direct insight	Respondents who stated this as a problem				
			All respon-dents *N* = 866	Autistic people n = 373	Family member or caregiver of autistic people n = 504	Education professional n = 184	Other respondent groups* n = 408
6	**Systemic expectations of schools, including rules, routines, and attendance requirements, mean that schools are not genuinely inclusive for autistic students** (e.g., inflexible rules and expectations; rigid learning structures)	*“There is a high level of cognitive effort that is required to adapt to a neuronormative environment and expectations, this can take a toll on my ability to process information and contribute to class discussions.”* (ID 164) *“I work with a participant who was expelled from his private Autism specific school because of problematic behaviours. He was unable to be placed in a school for 12 months due to hand over issues, poor communication between the institutions and lack of external advocacy.”* (ID 1121)	13%	11%	14%	15%	14%
7	**Curriculum is based on neurotypical standards and not suitable for, or sufficiently adjusted to, the learning needs of autistic children** (e.g., lack of choice for autistic children in the curriculum; lack of differentiation)	*“Crowded curriculum means people like me who learnt my own way at the back of the classroom have less freedom to find their own way through learning at school.”* (ID 77) *“Special interests are ignored, and opportunities to include autistic people are missed. We could run an entire lesson on our special interest but are constantly denied as it isn't part of the syllabus.”* (ID 162)	12%	11%	13%	16%	13%

Rank	Problems experienced by autistic people in relation to education and sample quotes from responses	Direct insight	Respondents who stated this as a problem				
			All respon-dents *N* = 866	Autistic people n = 373	Family member or caregiver of autistic people n = 504	Education professional n = 184	Other respondent groups* n = 408
8	**Bullying and lack of school approach to prevent bullying** (e.g., bullying by peers or staff; hostility towards autistic student)	*“Bullying - not just stopping the bullying, but facilitating processes that allow kids with ASD to be heard and understood (recognition that they can't respond the same way to neurotypical children and even communicating what has occurred is difficult.”* (ID 100) *“I was frequently stalked, bullied and beaten at school, including a video recording of me being surrounded by a circle of violent kids threatening to kill me. The school refused to punish any of the perpetrators in the recording because I had a nervous laugh (another common ND trait) and said that I ‘must have been enjoying myself’.”* (ID 1460)	11%	13%	11%	7%	12%
9	**Focus on behaviour, misinterpretation of behaviour, and use of behavioural strategies** (e.g., being excluded from class due to behaviours; lack of understanding of behaviour as communication)	*“Segregation, ostracism and humiliation due to hidden parts of our disability being seen as 'lazy' or 'fussy'. e.g., kids late to school due to sensory issues, and their 'favourite socks' feeling funny. Not their fault, and they shouldn't be punished or left out of school activities.”* (ID 147) *“Being excluded from preschools, primary school, very poor behavior support, poor communication with parents. Some parents have reported that some schools use cages for behavior management!”* (ID 1337)	10%	10%	12%	11%	11%

Rank	Problems experienced by autistic people in relation to education and sample quotes from responses	Direct insight	Respondents who stated this as a problem				
			All respon-dents *N* = 866	Autistic people n = 373	Family member or caregiver of autistic people n = 504	Education professional n = 184	Other respondent groups* n = 408
10	**An insufficient understanding of, or support for, autistic students' social preferences or social interactions** (e.g., lack of social supports; neurotypical social expectations)	*"Social difficulties - bullying, peer challenges, misunderstandings, difficulties arising from a strong sense of justice (i.e., 'dobbing', valuing fairness over harmony, etc)."* (ID 737) *"Not enough adults that understand the Double Empathy Problem, i.e., the difference between the two types of meaning-making systems typically used by neurodivergent and neurotypical people, thus negatively influencing social experiences at school."* (ID 1195)	10%	8%	8%	11%	10%

3.3.1.2 Factors causing the problems experienced by autistic people in relation to education

A total of 813 respondents opted to answer this question on education. This included 373 autistic people and 483 family members or carers of autistic people. The factors that respondents felt were causing or leading to the problems experienced by autistic people within education were coded into 19 categories, which fell under the following 15 broad areas:

- Teacher knowledge and attitudes towards autism, including a lack of understanding learning needs and negative perceptions of autistic students
- Lack of training in autism via university and/or professional development
- Education systems are designed for neurotypical children and the inclusion of autistic students is not prioritised
- Funding and resources for autistic students' educational needs are insufficient, difficult to access, and poorly distributed
- School environments are not designed for inclusion of autistic students
- Accommodations and supports for autistic students are insufficient
- Overstretched staff and resources, including classes being too large and teachers being overworked
- Teaching methods, learning activities, content, or assessment may not be suitable for autistic children, or accommodating of their needs
- Lack of society or community education about, or acceptance of, autism
- Lack of understanding of the heterogeneity of autism in terms of profile and needs
- Peers/others lack understanding of autistic social styles and preferences
- Schools are not communicating/collaborating with allied health professionals and/or disability services
- Schools are often focused on behaviour and the use of behaviourally based strategies
- Support is lacking for undiagnosed autistic students, and diagnosis is delayed by wait times and teachers' inability to recognise diverse autistic presentations (e.g., in females)
- Autistic students mask or conform to neurotypical standards.

Table 15 ranks the 10 most commonly reported factors that respondents felt were causing the problems that autistic people experience in relation to education reported above. The data are ranked from most frequently reported to least frequently reported problems across all respondents. The right-hand columns report the proportion of specific respondent groups that identified this as a problem.

Importantly, these data show that approximately:

1 in 4 respondents stated that the problems were due to educators and educational leaders lacking awareness and understanding about autism and associated needs.

1 in 4 respondents reported that the problems were due to a lack of training in autism via university and/or professional development.

Table 15: 10 most frequently reported factors causing the problems reported by autistic people in relation to education

Rank	Factors causing the problems experienced by autistic people in relation to education and sample quotes from responses	Direct insight	Respondents who stated this as a problem				
			All respondents *N* = 813	Autistic people n = 373	Family member or caregiver of autistic people n = 483	Education professionals n = 174	Other respondent groups* n = 391
1	**Educators and educational leaders lack awareness and understanding about autism and associated needs (including learning needs)** (e.g., poor/limited understanding of autism; lack of understanding of the challenges experienced)	*"Level of knowledge about autism amongst educators varies wildly and many have very little knowledge or experience in how to work with autistic students."* (ID 18) *"Not every teacher can be a speech therapist, but a greater understanding of communication and emotional needs of people who are neurodivergent would move towards an environment that fosters greater levels of education accessibility."* (ID 668)	28%	30%	27%	28%	29%
2	**Lack of training in autism via university and/or professional development** (e.g., lack of special needs trained teachers; lack of professional development on autism)	*"Educators are not provided with appropriate training on supporting autistic children within the classroom and have to 'learn on the job'."* (ID 303) *"Lack of training which results in children being seen as a deficit and it is a problem to have to try and teach them."* (ID 495)	24%	16%	28%	35%	25%

Rank	Factors causing the problems experienced by autistic people in relation to education and sample quotes from responses	Direct insight	Respondents who stated this as a problem				
			All respondents *N* = 813	Autistic people n = 373	Family member or caregiver of autistic people n = 483	Education professionals n = 174	Other respondent groups* n = 391
3	**Education system designed for neurotypical children resulting in challenges with both mainstream and segregated settings in meeting the needs of autistic children** (e.g., education is based on neuronormative brains and autistic brains have to adapt; education system is not adapted)	*“The push for inclusion that forces all students including autistic students to be put together in the same learning environment and then expecting that all students will thrive in that same environment.”* (ID 337) *“The way the mainstream education system has been built without regard to the needs of autistic people and pushes people whose brains and bodies work differently out. We now need to transform this system that has evolved this way for a long time and has entrenched exclusion.”* (ID 707)	21%	19%	22%	19%	19%
4	**Funding and resources for autistic students’ educational needs are insufficient, difficult to access, and poorly distributed** (e.g., funding is prioritised some autistic students [e.g., level 2] but not others [e.g., gifted]; funding can be mishandled or pooled with other students with disabilities)	*“Approach/process in determining whether a student/school gets additional funding from the DET is difficult for the school and families to navigate. It is also very time and resource intensive and families and schools do not necessary have the knowledge and time to address the process.”* (ID 714) *“Lack of funding for schools to provide even basic supports and reasonable adjustments to a child in the classroom.”* (ID 914)	19%	13%	22%	17%	18%

Rank	Factors causing the problems experienced by autistic people in relation to education and sample quotes from responses	Direct insight	Respondents who stated this as a problem				
			All respondents *N* = 813	Autistic people n = 373	Family member or caregiver of autistic people n = 483	Education professionals n = 174	Other respondent groups* n = 391
5	**School environments are not designed for inclusion of autistic students** (e.g., schools are loud; lack of sensory-friendly environments).	*"Re sensory issues - lack of understanding e.g., a (female) kid could prefer clothing that feels secure but uniform is a loose fitting dress. Only alternative option appears to be boys uniform but this has other social implications."* (ID 897) *"Lack of understanding and/or flexibility to accommodate changes to the sensory environment for autistic people. e.g., noisy corridors, not providing learning alternatives to participating in swimming carnivals (strong smells and noise), not providing accommodation alternatives on school camps to noisy bunk rooms."* (ID 1131)	11%	13%	11%	9%	11%

Rank	Factors causing the problems experienced by autistic people in relation to education and sample quotes from responses	Direct insight	Respondents who stated this as a problem				
			All respondents *N* = 813	Autistic people n = 373	Family member or caregiver of autistic people n = 483	Education professionals n = 174	Other respondent groups* n = 391
6	**Accommodations and supports for autistic students are insufficient, and the capacity, knowledge, and resources required to accommodate/support autistic students are lacking** (e.g., lack of ability/capacity to make accommodations; lack of understanding of how to support students)	*"I think a lack of flexibility around school rules and providing accommodations often comes from school staff not having adequate understanding/knowledge of autism (e.g., treating a student's sensory sensitivity as a behavioural problem they can choose not to do, or a student getting in trouble for not demonstrating 'whole body listening' rather than recognising they may find it easier to listen without making eye contact)."* (ID 817) *"There are tens of thousands of Non Verbal Autistic school students across the country, particularly in special schools who have NO means to communicate. Often, NO individualised AAC (high tech or low tech) & most teacher, special ED & assistants or aides aren't familiar with using an AAC's & the rights of the child to communicate, ALL day, every day, across every domain."* (ID 925)	10%	7%	10%	9%	13%

Rank	Factors causing the problems experienced by autistic people in relation to education and sample quotes from responses	Direct insight	Respondents who stated this as a problem				
			All respondents *N* = 813	Autistic people n = 373	Family member or caregiver of autistic people n = 483	Education professionals n = 174	Other respondent groups* n = 391
7	**Teachers are unsupported and overworked** (e.g., educators are time poor, under resourced, and overloaded)	*"Education staff are overworked, underpaid, and given no incentive to pursue continuous professional development opportunities."* (ID 532) *"Teachers don't have the time or the resources to support Autistic individuals and find it overwhelming. In many conversations with teachers they are typically empathetic and want to help, however they become exhausted because they find they can't do the things they need to do properly and so what they are able to do doesn't work."* (ID 1006)	10%	10%	10%	14%	9%
8	**Teaching methods, learning activities, content, or assessment may not be suitable for autistic children, or accommodating of their needs** (e.g., pedagogy is one-size-fits-all; teaching methods do not take into consideration challenges of autistic children [e.g., co-occurring ID])	*"A lot of vital information is given verbally during lectures and our processing is different. It can be hard to figure out what information is needed or how to capture it all while the lecture is happening."* (ID 330) *"Graphic/visual representations are really hard to get right but really important for students with certain learning styles as they might not function as just a 'reminder' of the concept the way it does for most, but to re-explain concepts over and over again that we fundamentally understand but cannot articulate well without prompting."* (ID 821)	9%	11%	7%	9%	8%

Rank	Factors causing the problems experienced by autistic people in relation to education and sample quotes from responses	Direct insight	Respondents who stated this as a problem				
			All respondents *N* = 813	Autistic people n = 373	Family member or caregiver of autistic people n = 483	Education professionals n = 174	Other respondent groups* n = 391
9	**Lack of society or community education about or acceptance of autism** (e.g., poor societal attitudes towards those who are divergent/different; societal unwillingness to change attitudes)	*“A dominant narrative of autism which is driven by non-autistic voices who are given disproportionate media coverage in relation to autistic issues.”* (ID 343) *“Social narrative around Autism being a disease or condition requiring cure instead of focusing on removing barriers to quality of life, celebrating strengths and being pro-autism in our acceptance of autistic people.”* (ID 1020)	8%	6%	7%	13%	9%
10	**Lack of understanding of the heterogeneity of autism in terms of profile and needs** (e.g., reliance on stereotypes; lack of awareness of the diversity of autistic students)	*“Poor understanding of ASD and its highly variable presentations (e.g., interpreting some as oppositional), especially in biological females.”* (ID 677) *“Every person is different on the Autism Spectrum. Why tick one box when there are millions to tick. Not all Autistics are the same.”* (ID 863)	7%	7%	7%	8%	6%

Note. *all other groups that have not been identified separately

3.3.1.3 Factors that could prevent or reduce the problems experienced by autistic people in relation to education

A total of 788 respondents opted to answer this question on education. This included 318 autistic people and 459 family members or carers of autistic people. The factors that respondents identified as preventing or reducing the problems experienced by autistic people in relation to education were coded into 18 categories. These categories fall under the following 11 broad areas:

- Increasing awareness and knowledge of autism across the education system
- Increasing and improving funding and resources to provide autistic students with the staff and environment they need for an equitable learning experience
- Ensuring education is informed by autistic teachers, consultants, policy/curriculum planners, and leaders in education
- Ensuring schools are designed to minimise sensory overwhelm and include spaces that autistic people feel safe
- Reducing class sizes and increasing the number of teachers and aides/support staff in classes
- Changes to curriculum, instruction methods, assessment methods, and pedagogy to support autistic students and their learning needs
- Increasing collaboration, communication, and supportive relationships between autistic students, parents, educators, and allied health professionals
- Enhancing provision of accommodations and supports, including increasing flexibility around delivery and accommodations
- Changes at government/sector level including improved communication, training, and multiple options for education settings designed to support autistic students
- Increasing student access to autism diagnosis by improving teacher identification of autism, waiting list times, cost, and understanding of different autism presentations
- Using collaborative and supportive behaviour strategies and understanding reasons for behaviours.

Table 16 ranks the 10 most commonly reported factors that respondents reported could prevent or reduce the problems that autistic people experience in relation to education reported above. The data are ranked from most frequently reported to least frequently reported problems across all respondents. The right-hand columns report the proportion of specific respondent groups that identified this as a problem.

Importantly, these data show that there was a clearly predominant factor highlighted by respondents:

Over 2 out of every 5 respondents identified increasing pre-service and in-service training on autism for all school staff as a factor that could prevent or reduce the problems experienced by autistic people in relation to education.

Table 16: 10 most frequently reported factors that could prevent or reduce problems experienced by autistic people in relation to education

Rank	Factors that could prevent or reduce the problems experienced by autistic people in relation to education and sample quotes from responses	Direct insight	Respondents who stated this as a problem				
			All respondents *N* = 788	Autistic people n = 318	Family member or caregiver of autistic people n = 459	Education professionals n = 173	Other respondent groups* n = 359
1	**Increasing pre-service and in-service training on autism for all school staff, and especially for educators** (e.g., training for staff/teachers/lecturers/tutors; training in university)	*"Increased PD for ALL educators on the broader issues of neurodiversity, most notably its heterogeneity and that one strategy is not EVER appropriate for EVERY student."* (ID 354) *"Making PD on the issues that Autistics have with accessing appropriate education, and solutions, compulsory for all educators."* (ID 385)	41%	37%	42%	47%	45%
2	**Increasing educator and broader community awareness and acceptance of autism, and treating autistic students with respect, kindness, tolerance, and empathy** (e.g., teach acceptance rather than trying to change neurodivergent individuals)	*"Public education and awareness programs to increase understanding of the diversity of autistic experience."* (ID 343)	18%	17%	16%	19%	16%
3	**Increased and improved funding and resources to provide autistic students with the staff and environment they need for an equitable learning experience** (e.g., funding to address sensory environment [light/sounds/sensory rooms]; funding for teachers' aides)	*"Funding should be provided to schools to address the sensory aspects of the environments e.g., sounds, light, quiet spaces, sensory rooms."* (ID 14) *"Better funding for LEARNING issues. Such as tutors at School or experienced Teacher Aides and give them the time they actually have been assigned for that child."* (ID 793)	18%	14%	20%	23%	18%

Rank	Factors that could prevent or reduce the problems experienced by autistic people in relation to education and sample quotes from responses	Direct insight	Respondents who stated this as a problem				
			All respondents *N* = 788	**Autistic people** n = 318	**Family member or caregiver of autistic people** n = 459	**Education professionals** n = 173	**Other respondent groups*** n = 359
4	**Actively consulting and collaborating with autistic and neurodivergent people, and employing more autistic teachers, consultants, policy/curriculum planners, and leaders in education** (e.g., ask autistic people what they need and implement this; autistic input into school building design)	*“it should be a requirement that a certain percentage of staff fly under the neurodivergent flag themselves. Not only does this lend an autie voice to the situation academically speaking (thus supporting the different ways auties learn or require support), it provides openly proud auties to be role models for not only ND children but also to NT children which can only lessen bullying and promote acceptance.”* (ID 63) *“Inclusion of the autistic voice as standard. Not 'increased' Inclusion - this should be a non-negotiable prerequisite. ‘Nothing about us without us.’”* (ID 68)	15%	23%	14%	17%	16%
5	**Ensuring schools are designed to minimise sensory overwhelm and include spaces that autistic people feel safe and comfortable** (e.g., environment modifications; quiet spaces enabled by universal design principles)	*“A purpose built sensory room in every school, where autistic students can go to have some quiet time.”* (ID 530) *“Foster a more relaxed learning environment that is not the traditional desk set up. Allow the students to go to a safe place when needed whether it's outside or in an area in the room.”* (ID 594)	13%	15%	13%	15%	12%
6	**Reducing class sizes and increasing the number of teachers and aides/support staff in classes** (e.g., reducing class sizes benefits everyone; more aides for autistic students)	*“If schools reduced class sizes this would produce a lot of welcome change and opportunity. Reducing class sizes benefits everyone - students, teachers and other staff, as well as anyone in those cohorts who also happens to be autistic or neurodivergent.”* (ID 72)	11%	8%	12%	13%	9%

Rank	Factors that could prevent or reduce the problems experienced by autistic people in relation to education and sample quotes from responses	Direct insight	Respondents who stated this as a problem				
			All respondents *N* = 788	Autistic people n = 318	Family member or caregiver of autistic people n = 459	Education professionals n = 173	Other respondent groups* n = 359
7	**Adapting pedagogy, instruction, and assessment to better meet the needs of autistic students** (e.g., neurodivergent pedagogy will benefit all students; permit alternative assessment types)	*"Develop autistic style teaching methods."* (ID 477) *"Making educational content available in a range of contexts - lectures, videos, readings, images, hands on doing."* (ID 664)	11%	13%	11%	10%	9%
8	**Increasing and improving education, information, and research on autism** (e.g., additional autism research; neurodivergence education)	*"More research should be done with diverse communities to better define Autism and give a clearer picture of this neurodivergence."* (ID 767) *"Educate the wider community about autism, break down the fear and stigma associated with a diagnosis."* (ID 1443)	11%	9%	13%	8%	12%
9	**Increased collaboration, communication, and planning between autistic students and their parents, teachers, and allied health team** (e.g., listen to parents as they are experts on their child; all stakeholders planning together)	*"More in depth conversations with parents/ guardians/ students with a carefully chosen team so that parents aren't having to explain everything to each teacher every term for the rest of the schooling life. It's exhausting, particularly for parents who are autistic."* (ID 1081) *"Establishment of better and more regular avenues of communication between school teachers, service providers and families."* (ID 1542)	11%	5%	7%	8%	5%

Rank	Factors that could prevent or reduce the problems experienced by autistic people in relation to education and sample quotes from responses	Direct insight	Respondents who stated this as a problem				
			All respondents *N* = 788	Autistic people n = 318	Family member or caregiver of autistic people n = 459	Education professionals n = 173	Other respondent groups* n = 359
10	**Increasing accommodations/individual plans for autistic students, as well as understanding of how and why to make these accommodations** (e.g., allowing personalised adjustment [not standard adjustments]; information for teachers on what accommodations autistic students may need and why they are important)	*"Allowing adjustments that are meaningful and personalised to actually help the individual rather than just selecting standard adjustments."* (ID 41) *"Information made available to educational professionals as to the likely requests from [neurodivergent people] for alternative treatment, and the reasons why such requests are not simply special pleading, but in fact a [sensible] way of assessing the true capabilities of [neurodivergent people]."* (ID 308)	10%	11%	10%	7%	12%

Note. *all other groups that have not been identified separately

3.3.1.4 Factors that are working well, or have worked well, for autistic people in relation to education

A total of 702 respondents opted to answer this question on education. This included 285 autistic people and 418 family members or carers of autistic people. The factors that, when available, are reported to be working well, or have worked well, for autistic people in relation to education were coded into 12 categories, each falling under its own broad area:

- When educators have knowledge about autism, value autistic students, and treat autistic students well
- When accommodations are made and autistic students are supported at school
- When the curriculum, pedagogy, and instruction methods are tailored to autistic students' needs
- When attitudes or approaches to supporting autistic students are positive or neurodiversity affirming
- When education institutions, health and disability professionals, autistic adults, and families collaborate to support and listen to the autistic student
- When the physical environment is adapted to autistic sensory needs
- When learning delivery structures, modes, and locations suit the autistic student
- When autistic students' education is supported by policies, laws, leadership, and/or funding
- Nothing/not much/unsure
- When the education system works for the autistic student
- When class sizes are small and autistic students have 1:1 support from staff
- When autistic students are supported to form strong social relationships at their place of education, free from bullying and criticism.

Table 17 ranks the 10 most commonly reported factors that respondents reported to be working well, or have worked well, for autistic people in relation to education. The data are ranked from most frequently reported to least frequently reported factors that are working well across all respondents. The right-hand columns report what proportion of specific respondent groups reported this as a factor that is working, or has worked well.

Importantly, these data show that approximately:

1 in 3 respondents stated that one thing working well in education for autistic people is when educators have knowledge about autism, value autistic students, and treat autistic students well..

Almost 1 in 4 stated that when accommodations are made, and autistic students are supported at school, education works well for autistic students.

Table 17: 10 most frequently reported factors that are working well, or have worked well, for autistic people in education

Rank	What is working well, or has worked well, for autistic people in education, and sample quotes from responses	Direct insight	Respondents who stated this as a problem				
			All respondents *N* = 702	Autistic people n = 285	Family member or caregiver of autistic people n = 418	Education professionals n = 166	Other respondent groups* n = 335
	When educators have knowledge about autism, value autistic students, and treat autistic students well (e.g., when educators have positive attitudes towards autistic students; when autistic students are valued intrinsically and not pressured to conform or change)	*"Individual educators who care and have lived experience."* (ID 1545) *"As a professional advocate who often delivers PD on Neurodiversity to teachers, I am seeing an increasing number of them who are pretty passionate about learning more, and I am always very enthusiastic in affirming this when I meet them."* (ID 1467)	34%	29%	34%	34%	37%
2	**When accommodations are made, and autistic students are supported at school** (e.g., when accommodations are made for autistic students around assessments/ environment/curriculum; accommodations for communication methods)	*"Adaptations to assessment and curriculum that are person-centred and respond to the individual communication and sensory needs of the student."* (ID 1521) *"There is now a greater focus on accommodations and an awareness of the challenges for autistic people via personalised learning plans."* (ID 151)	24%	25%	24%	24%	25%
3	**When the curriculum, pedagogy, and instruction methods are tailored to autistic students' needs** (e.g., being flexible around learning processes; ensuring instruction is clear and direct)	*"Educators who … acknowledge that [neurodivergent] individuals learn differently and that can include needing to move, sensory changes, and executive functioning support." (ID163)* *"For my child, child-directed learning. He learns an incredible amount but not in 'conventional' ways."* (ID 1170)	18%	24%	16%	16%	16%

Rank	What is working well, or has worked well, for autistic people in education, and sample quotes from responses	Direct insight	Respondents who stated this as a problem				
			All respondents *N* = 702	Autistic people n = 285	Family member or caregiver of autistic people n = 418	Education professionals n = 166	Other respondent groups* n = 335
4	**When attitudes or approaches to supporting autistic students are positive or neurodiversity affirming** (e.g., when positive attitudes are taught to students; positive attitudes towards behaviour)	*"Higher profile/raised awareness of autism through campaigns, charitable works, celebrities (e.g., Chloe Hayden) and media (e.g., TV shows like The A Word or Atypical)."* (ID 673) *"I think peers are getting better at understanding their Neurodiverse peers (bullying aside). This doesn't help the students who don't openly identify as Autistic/ND, but I believe that student peer attitudes are shifting somewhat."* (ID 1157)	17%	14%	15%	24%	16%
5	**When education institutions, health and disability professionals, autistic adults, and families collaborate to support and listen to the autistic student** (e.g., collaboration with the autistic student, all stakeholders, allied health professionals, educators, autistic adults, parents)	*"Timely, regular, clear, concise communication and shared goals between educational staff, parents and support personnel (therapists, support workers)."* (ID 654) *"IEP meetings where the student is present and is empowered to speak for themselves and is seen as capable of doing so and is listened to. [This] began to happen from about year 9, for my [oldest] child, to a degree."* (ID 1419)	16%	12%	17%	24%	17%

Rank	What is working well, or has worked well, for autistic people in education, and sample quotes from responses	Direct insight	Respondents who stated this as a problem				
			All respondents *N* = 702	Autistic people n = 285	Family member or caregiver of autistic people n = 418	Education professionals n = 166	Other respondent groups* n = 335
6	**When the physical environment is adapted to autistic sensory needs** (e.g., better access to low sensory spaces/ break out spaces)	*"My art teacher let me sit in the art room by myself during lunch times. [I] could unmask, and either have a space where I could more easily focus on my assignments, or where [I] could be creative."* (ID 70) *"Classrooms that have a quiet space, allow fidget toys and movement breaks, dimmer lights, have visual [schedules], allow noise cancelling headphones, allow alternative to school uniforms and school shoes if there is a sensory issue around clothing."* (ID 427)	14%	18%	14%	12%	15%
7	**When learning delivery structures, modes, and locations suit the autistic student** (e.g., when delivery modes and locations are flexible and suit the autistic student, including flexible/non face-to-face delivery modes/off campus and distance locations)	*"Online/self paced learning has been amazing for myself and many Autistic people I know. It allows engagement as a pace that suits us and revision of verbal instruction is easier. There is less energy spent on masking and putting up with the barriers and more on learning the content."* (ID 772) *"Managed attendance - acknowledging that education is exhausting for students and allowing managed attendance is consultation with families."* (ID 702)	13%	15%	14%	7%	11%

Rank	What is working well, or has worked well, for autistic people in education, and sample quotes from responses	Direct insight	Respondents who stated this as a problem				
			All respondents *N* = 702	Autistic people n = 285	Family member or caregiver of autistic people n = 418	Education professionals n = 166	Other respondent groups* n = 335
8=	**Nothing/not much/unsure**	*"Not much to be honest. Mostly these are bandaid strategies that work for that environment at a superficial level. This causes other problems later in life because real skills are not developed - lower rates of employment, education, etc. and social isolation, anxiety, depression, misdiagnosis, suicide, and all sorts of other damage."* (ID 627) *"Nothing has worked for me. I spoke to the teacher, spoke with the co-ordinator, wrote letters, nothing was done and they shrugged it off."* (ID 1039)	12%	7%	12%	16%	13%
8=	**When autistic students' education is supported by policies, laws, leadership, and/or funding** (e.g., specific policies such as the Disability Act and Victorian Disability Inclusion Policy)	*"Some progress in policies recognising that support for disabled students needs to extend beyond the classroom and include the school environment and participation more broadly (as seen in the recent Victorian Disability Inclusion policy)."* (ID 246) *"The principal of his school is passionate about supporting people with disabilities to achieve equitable access to the curriculum, and achieve their goals."* (ID 1251)	12%	14%	13%	9%	11%

Rank	What is working well, or has worked well, for autistic people in education, and sample quotes from responses	Direct insight	Respondents who stated this as a problem				
			All respon-dents *N* = 702	Autistic people n = 285	Family member or caregiver of autistic people n = 418	Education profession-als n = 166	Other respondent groups* n = 335
10	**When the education system works for the autistic student** (e.g., increased discussion around school systems for autistic students; availability of different school systems)	*"At the time he was in year 9 it was recognised he was struggling both socially and academically and was finally removed from the mainstream classes and placed in Special ED class where he started thriving at long last. This recognition should have come much earlier."* (ID 1119)	11%	8%	12%	13%	9%

Note. *all other groups that have not been identified separately

3.3.2 Umbrella review: Primary and secondary education

Autism CRC project Identifying autistic learners' educational strengths, needs and challenges: Supporting engagement and removing barriers in Australian schools (due for completion in July 2023) has conducted comprehensive scoping review on seven topic areas related to education:

i) Academic and learning considerations
ii) Built environment and learning space design considerations
iii) Student well-being considerations
iv) Co-occurring considerations
v) Identity considerations
vi) Family and community considerations
vii) Inclusive practices.

This umbrella review therefore focused upon teachers' knowledge of and attitudes towards autism. This included their perception and experience of autism-specific training. The need for this was based upon the findings of the previous umbrella reviews in this document, many of which have consistently highlighted autism knowledge and training on autism as critical for positive outcomes. The findings of this umbrella review are synthesised in Table 18.

The focus of this review was on teacher factors related to autism that could impact learning (e.g., attitudes, knowledge, training), rather than on specific interventions to support learning outcomes. The terms used for the searches and the number of articles identified, screened, and included are provided in Appendix E-1 and Appendix E-2. The final umbrella review reports on 12 systematic reviews, two of which were led by Australian authors. All of the systematic reviews were written in the last five years. The 12 systematic reviews collectively report on 285 individual studies.

The information and findings from the included reviews are summarised in the subsections below. When reporting on the number of people or participants in the review, this will be represented as *n* = [number of participants]. When reporting on the number of reviews that considered a topic, this will be represented as *k* = [number of reviews].

3.3.2.1 Participants within included reviews

Of the 12 reviews, only six provided details on the number of teachers who participated. In total, these six reviews included 20,236 teachers as participants, with sample size for individual studies ranging from 2 to 866 (*M* = 3,372.67; *SD* = 2,065.19). Only four systematic reviews provided information on the gender of the teachers; most of the teachers in these reviews were female (average percentage = 76.60%).

3.3.2.2 Quality of included reviews

The quality of the included systematic reviews was assessed using the JBI Critical Appraisal Tool for Systematic Reviews. This tool assesses the methodological quality of a systematic review. The maximum score is 33, which indicates a very high-quality systematic review. The average quality score for the 14 included systematic reviews was 25.21 (76.29%), with the quality score ranging from 19 to 30.

3.3.2.3 Topics of included reviews

The 12 reviews identified in the area of teacher attitudes, knowledge, training on autism covered three topics; some reviews discussed multiple topics. These were the educational professionals' level of knowledge of autism and attitudes towards autistic students (*k* = 9); the impact of educational professionals' level of knowledge of autism and attitudes towards autistic students (*k* = 4); and autism-specific training for educational professionals (*k* = 7).

3.3.2.4 Research gaps

The 12 reviews identified a number of research gaps, which are combined with research gaps identified by the authors of this report and summarised in Table 18.

The focus of this umbrella review was around teacher knowledge and attitudes. The research highlighted how teachers, autistic students and their family members feel that educational staff have limited knowledge of autism and that this is impacting the ability for every autistic student to have the accommodations and supports that they would benefit from. This highlights a need for a large scale teacher knowledge and attitudes survey in Australia, with a companion survey for autistic students assessing the impact of their teacher's knowledge on their academic outcomes and attendance. However, this work should not delay research into improving teacher knowledge of autism and attitudes towards autistic students through co-developed and co-delivered training. As with any training, the impact of which should be assessed through subjective and objective methods.

Table 18: Umbrella review findings for primary and secondary education

Topic	Number of reviews on topic; citations	Key findings	Key research gaps identified
Educational professionals' level of knowledge of autism and attitudes towards autistic students	k = 9 Blumenthal (2019) Genovesi et al. (2022) Gomes-Mari et al. (2021) Holmqvist (2022) Han & Cumming (2022) Luddeckens (2021) Richter et al. (2019) Russell et al. (2022) Tomlinson et al. (2020)	• The majority of teachers have a positive attitude towards teaching autistic students; 87% of teachers report a positive attitude in one Australian study • Most teacher demographics, including years of experience, do not predict positive attitudes towards autistic students • Teacher knowledge of autism significantly varies. One review describes knowledge levels as "low to moderate". A separate study reported mean accuracy scores of 46% for general education teachers and 35% for special education teachers • Teachers have even more limited knowledge of how autism presents in females • Many teachers find it hard to differentiate autism-specific needs from general needs of students with developmental disabilities	• Large-scale quantitative studies of teacher knowledge and attitudes towards autistic students using unbiased samples (i.e., total staff population from a specific area). Autism knowledge and attitudes should be assessed through a measure co-developed with autistic students to ensure it contains items which autistic students think would improve their school experience • Knowledge and attitudes of teachers in secondary schools, and those outside of metropolitan areas • Knowledge and attitudes of non-teaching school staff with whom autistic students may interact • Knowledge and attitudes of how autism may present differently dependent upon age, gender, and other intersectionality
The impact of educational professionals' level of knowledge of autism and attitudes towards autistic students	k = 4 Han & Cumming (2022) Nuske et al. (2018) Richter et al. (2019) Tomlinson et al. (2020)	• Students have stronger and more trusting relationships with staff who have a greater understanding of the needs of autistic students • Parents also report increased trust of teachers with good knowledge of autism • Autistic students feel that teachers' knowledge of autism influences the quality of their educational provision • Teachers with lower autism knowledge report less confidence in teaching autistic students and feel less able to select and implement appropriate strategies • Both autistic students and parents report that inaccurate or poor knowledge of autism, or a lack of knowledge of how autism differs based on gender or co-occurring conditions, has led to teachers not providing specific accommodations. It has also led to misinterpretation of autistic behaviour as opposing behaviour. These can both then impact upon student well-being and attainment	• How autistic students assess their teachers' knowledge and understanding of autism • Impacts of level of teacher knowledge of autism on measurable student outcomes like absenteeism and academic progress • Impact of teacher knowledge of autism on the sensory aspects of a classroom (e.g., the level of noise, lighting etc.) • Multi-informant approaches, e.g., links between teacher attitudes, previous training/professional learning on autism, and specific student experiences of education, including belonging.

Topic	Number of reviews on topic; citations	Key findings	Key research gaps identified
Autism-specific training for educational professionals	k = 6 Blumenthal (2019) Petersson-Bloom & Holmqvist (2022) Kossyvaki (2021) Nuske et al. (2018) Richter et al. (2019) Russell et al. (2022)	• One review describes initial teacher education programs as "inadequate" for preparing teachers to support autistic students in their classrooms • Educational professionals identify a lack of specific training on autism and a desire to access more high-quality, accessible training which helps them to support autistic students • Those who have received previous autism-specific training score better on measures of autism knowledge, are more accepting of diversity and difference, and report more self-efficacy for supporting autistic students • Everyone in a school, not just teachers, should have access to autism training	• What autistic students would like school staff (and their peers) to learn in autism training • Co-development and evaluation of autism-specific professional development for all staff working in schools (i.e., not just teachers) and for those training to be teachers. Evaluation should include measures of knowledge, attitudes, and self-efficacy for supporting autistic students. Such training should address intersectionality and its impact upon the presentation and support needs of autistic students • The impact of integrated training on neurodiversity and autism within initial teacher education (i.e., rather than just a single lecture in initial teacher education, evaluating the impact of discussing and reflecting on neurodiversity and/or autism throughout multiple courses in teacher training) • Effectiveness of autism-specific training for teachers in secondary schools, and those outside of metropolitan areas • Evaluating the outcome of training through ecologically valid measures e.g., asking teachers to design an autism-friendly classroom pre-post training, asking teachers to recommend tailored accommodations based on a student profile pre-post training

Note: Co-development in this context means with the autistic and autism community and with people who will receive the training (i.e., educational staff).

3.3.3 Policy and guideline review: Primary and secondary education

The separate Autism CRC project Identifying autistic learners' educational strengths, needs and challenges: Supporting engagement and removing barriers in Australian schools (due for completion in July 2023) identified state/territory inclusive education policy documents and analysed with regard to:

i) the UNESCO (2017) Guide for Ensuring Inclusion and Equity in Education,
ii) the social model of disability,
iii) definition of inclusive education (CRPD/GC4),
iv) context.

So that the gap analysis between research and policy could be undertaken, an overview of state and federal education policy as it relates to autism and broader disability is provided below. The policy overview is summarised in Table 19.

The policies and guidelines summarised were produced at a state and territory level, excepting three national level policies. State and territory level policies were produced by state/territory governments, and by state/territory Departments of Education. Information within the identified policies relevant to autistic individuals and/or people with disability is summarised below and in Table 19.

Publication dates were provided for 78% (k = 25) of the policies included in this review (k = 32). Of these 25 dated policies, 84% (k = 21) were published in the past five years (2018–2023). The overall publication range for the 25 dated policies was 2016–2023. Information about autism specifically was included in 34% of policies (k = 11), while information about disability more generally was included in 97% of policies (k = 31). Both autism and disability were discussed in 31% of policies (k = 10). Aside from the three national level policies, the policies were distributed by state/territory as follows: seven from Queensland, five from the Australian Capital Territory, four from New South Wales, three from Western Australia, three from South Australia, two from the Northern Territory, one from Tasmania and four from Victoria. While additional policies were considered during this review, only those that provided: a) information relevant to either autistic people or people with disability; and b) additional unique information over and above that already summarised in Table 19, were included.

Of note is that policies specific to autism produced by the Australian Government Department of Education were not identified during our policy overview. The three national level policies included in this review produced by the Australian Government did not contain information about autism. Therefore, no national level autism-specific education policies were identified. State and territories identified as producing only one such policy include: Queensland, the Australian Capital Territory, New South Wales, South Australia, the Northern Territory and Tasmania. Two Western Australian policies containing autism-related information were identified, and three Victorian policies. The single Tasmanian policy was produced by the Tasmanian Government. One policy produced by the Tasmanian Government Department for Education, Children and Young People (DECYP) (*Department of Education Strategic Plan 2022–2024*) was identified but was found not to contain information on autism or disability and is not included in this review.

There is, therefore, a paucity of autism-specific educational policies within Australia to guide educational practice. Additional policies either: may not be available, may only be accessible to employees, or may be difficult to access or find. If the latter, stakeholders, such as education professionals working in Tasmania for DECYP, may have difficulty applying appropriate policies in their work with autistic students.

3.3.3.1 Policy and guideline relevant to autistic people

The 11 policies including information about autism contain the following key points (see Table 19 for more information):

- Autistic students need reasonable adjustments/accommodations at school and require funding for these adjustments/accommodations. While schools cannot diagnose autism, they can impute autism as a means to providing students with adjustments/accommodations, if this is required
- Several states offer autistic students access to small groups or specialist/intensive programs, usually as streams/satellite classes within mainstream primary and secondary schools. Where information about these programs is provided, such as in the NT Review of Policy and Practice for Students with Additional Needs, content reportedly focuses on autistic students' social skills, routines and repetitive behaviours, sensory needs and learning styles rather than such classes being for the benefit of academic or well-being outcomes
- Policies from several states emphasise the importance of building capacity/expertise of teachers to educate autistic students, through:
  - Professional learning
  - Targeted resources
  - Collaboration with Autism consultants.
- Data on autistic students suggests they:
  - Are less likely to finish Year 12 than non-autistic students
  - Often change schools to have their educational needs met
  - Are more likely to disengage from school than non-autistic students
- Only one policy document, the Victorian Autism Education Strategy, specifically mentions inclusion strategies for autistic students, such as: celebrating the diversity autistic students bring to school communities, supporting the well-being of autistic students, and collaborating with autistic students and their families.

3.3.3.2 Policy and guideline relevant to people with disability

The 30 education policies including information about disability contain the following key points (see Table 19 for more information):

- Essential to the well-being and learning outcomes of students with disability is that parents, students and teachers collaborate in equal partnership, and are all involved in decision-making about the students' education. In particular, students with disability need to have choice and control over their educational experiences, and clear pathways by which to raise concerns/complaints

- Schools should be inclusive environments, free of discrimination, where all staff understand and welcome diverse students, including those with disability. Schools should actively and intentionally foster positive beliefs and attitudes towards disability
- Schools must be equitable, and therefore ensure students with disability can access learning, events, activities, and buildings on the same basis as students without disability
- Teachers need more support, professional learning and resources to meet the educational needs of students with disability, particularly with regards to providing differentiated and flexible teaching approaches
- Students with disability, their families and representatives, have reported numerous barriers to school inclusion, such as:
    - Schools not fully embracing inclusion
    - Teachers needing more resources and training to create inclusive and equitable learning environments
    - Students not receiving appropriate supports without a medical diagnosis
- There needs to be a shift within schools from a deficit-based understanding of disability, to a strengths-based understanding, where the perspectives of students with disability are elevated and valued
- There is little consensus or research on how to measure learning outcomes in students with disability. In addition, NAPLAN data is not published for students with disability
- There is a need for stronger, and more collaborative relationships between schools and the NDIS.

Table 19: Policy and guideline review findings for primary and secondary education

Organisation level	Organisation name	Policy name	Policy date	Reference to autism	Reference to disability	Relevant information
Federal	Australian Government Productivity Commission	Review of the National School Reform Agreement: Study report	2022	×	✓	• Governments have committed to a high equity schooling system, with equity in outcomes across student cohorts, including students with disability • Data from the Australian Institute of Health and Welfare show that, as at 2018, 68% of 20-24 year olds with disability had completed Year 12 or equivalent, compared with 85% of 20-24 year olds without disability • Government should focus on lifting outcomes for students who are not meeting basic levels of literacy and numeracy, including those with disability • School systems should strive to eliminate discrimination of all kinds and to ensure differences in educational outcomes associated with students' culture, disability, remoteness, or socioeconomic status are reduced or eliminated • Students with disability are identified as a priority equity cohort, but NAPLAN performance data is not published for students with disability. This means it is not possible to know if the reforms are effective. • Difficulty accessing education that meets student learning needs in remote areas, particularly for Aboriginal and Torres Strait Islander children with disability • There is a need for consultation and shared decision-making with students with disability in relation to the design of educational outcomes • Students with disability should be present in all levels of government decision making • Many students, including those with disability, experience poor well-being which can impact a child's capacity to learn • Given the increasing number of students with disability attending their local school, it is time to review the content of "inclusion" units of study in Initial Teacher Training • There needs to be more targeted professional development, such as to support teachers to respond to diverse needs in the classroom • There is a shortage of teachers who are qualified to teach particular student cohorts • Data of school disciplinary absences should be disaggregated for student groups who face increased rates of exclusionary practices, including those with disability.

Organisation level	Organisation name	Policy name	Policy date	Reference to autism	Reference to disability	Relevant information
Federal	Australian Government	Disability Discrimination Act 1992	1998	×	✓	• It is unlawful for an educational authority to discriminate against a person on the ground of the person's disability: (a) by refusing or failing to accept the person's application for admission as a student; (b) in the terms or conditions on which it is prepared to admit the person as a student; (c) by denying the student access, or limiting the student's access, to any benefit provided by the educational authority; (d) by expelling the student; or (e) by subjecting the student to any other detriment • It is unlawful for an education provider to discriminate against a person on the ground of the person's disability: (a) by developing curricula or training courses having a content that will either exclude the person from participation or subject the person to any other detriment; or (b) accrediting curricula or training courses having such content.
Federal	Australian Government Department of Education	Disability Standards for Education 2005	2021	×	✓	• The government will seek to empower and support students with disability and their families by: (a) providing information for students with disabilities and their families on student's rights, (b) providing clearer rules on consulting with students with disability and their families and handling issues and complaints; (c) sharing information when students change schools • The government will strengthen the knowledge and capability of educators and providers by: (a) developing information products on the Standards that explain the responsibilities of education providers; (b) training on the Standards for school-teachers and leaders; (c) including the Standards in higher education policies and practices. • The government will seek to ensure more accountability for the Standards throughout education by: (a) making sure education policies match the Standards; (b) improving vocational education and training for students with disability; (c) providing more public information on how schools support students with disability; (d) collecting and reporting data about school students with disability; (e) checking how well the Standards are followed. • The government will build awareness and capability in the Early Childhood Education and Care (ECEC) sector by: (a) providing information for parents and carers about their children's rights; (b) providing information for ECEC providers; (c) making sure ECEC policies match the Disability Discrimination Act; (d) changing the Standards to include ECEC.

Organisation level	Organisation name	Policy name	Policy date	Reference to autism	Reference to disability	Relevant information
State	Queensland Government, Department of Education	Inclusive Education Policy	2021	×	✓	• As different student groups experience different barriers to inclusion, the department will continue to implement strategies and policies, and support practices that address the unique needs of students with disability • Children and young people across Queensland, from all social, cultural, community and family backgrounds, and of all identities and abilities can: (1) attend their local state school and education centre and be welcomed, (2) access and participate in a high-quality education and fully engage in the curriculum alongside their similar aged peers, (3) learn in a safe and supportive environment, free from bullying, discrimination or harassment, (4) achieve academically and socially with reasonable adjustments and supports tailored to meet their learning needs.

Organisation level	Organisation name	Policy name	Policy date	Reference to autism	Reference to disability	Relevant information
State	Queensland Government, Department of Education	Every Student with Disability Succeeding Plan 2021-2025	2021	×	✓	• This document is highly relevant and detailed: the below is a summary of the critical points in this document • Setting Expectations: To foster and inclusive culture which respects diversity and acknowledges that with the right support, every student with disability can succeed we will: (a) Develop materials to promote inclusion of students with disability in school communities, (b) Provide training to all departmental staff, including school staff, to understand and apply human rights in a practical setting and embed human rights within the school curriculum, (c) Monitor the use of Individual Curriculum Plans and provide training on their appropriate use, (d) Engage with schools and parents to undertake a line of inquiry into part-time educational programs and informal part-time school attendance arrangements to inform future actions • Building capability: To support schools and build the confidence and capability of staff to provide the right support as children and young people transition through each stage of learning we will: (a) Introduce tele-practice to increase access to departmental therapy services in rural and remote schools, (b) Increase students access to well-being and mental health support at school through the implementation of the Student Well-being Package, (c) Build the capacity of teachers to use Information and Communications Technology tools to enhance access and engagement of students with disability • Collaborating with students, parents, and the community: To ensure students with disability and their families are heard and are engaged as equal partners in improving outcomes we will: (a) Develop and implement guidelines to support schools to consult effectively with students with disability and their parents and carers, (b) Revise complex case management guidelines to strengthen collaboration between schools, students, parents, and external service providers, (c) Hold regular roundtables with students, parent groups and advocates of students with disability to hear their views and about system reforms, (d) Engage a non-government organisation to provide independent advocacy services to students and parents with complex concerns, (e) Engage a non-government organisation to provide support to families and students with disability and of children registered in ECDPs to understand inclusion and to engage with the schools, (f) Co-design communication materials for Aboriginal and Torres Strait Islander parents and carers about the supports provided at schools for students with disability.

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State	Queensland Government, Department of Education	Signposts for School Improvement: Inclusive Education	2022	×	✓	• In schools that are leading in inclusive education: • All staff have a deep understanding of the diversity of their school and ensure access, participation, representation, and engagement for all staff, students, parents, carers, and community members • Students have access to assistive technology and multiple ways to demonstrate their learning • Students, parents, carers and relevant external agencies are involved in collaborative consultation that results in informed decision making for support and adjustments being provided for learning, engagement, and well-being.
State	Queensland Government, Department of Education	Every Student Succeeding	2022	×	✓	• Availability of the Autism Hub to support autistic learners.
State	Queensland Government, Department of Education	Queensland Department of Education Strategic Plan 2018 - 2022	2018	×	✓	• We will achieve growth in students' learning by continuing to support students with disability to succeed by setting clear expectations, building teacher capacity and partnering with parents.
State	Queensland Government, Department of Education	Queensland Department of Education Strategic Plan 2021 - 2025	2021	×	✓	• Inclusion: Inclusive environments where diversity is valued, all are welcome and human rights protected • Embrace diversity: Harnessing the experience, skills and perspectives of diverse cultures, languages, abilities and identities.

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State	Queensland Government, Department of Education	Students with Disability – Reasonable adjustments resourcing. Information for students and families	N/A	✓	✓	• Schools can access a wide range of specialists from regional offices including therapists, nurses, Principal Advisors Autism and Principal Advisors Mental Health • A school can impute a disability if they have reasonable grounds, supported by evidence, to make such a judgement. The evidence must demonstrate that the student's need for adjustment(s) has been identified and arises from characteristics of disability. Schools cannot diagnose a disability such as autism, intellectual disability, mental health conditions or ADHD. Instead, schools are identifying whether the adjustments they are making address the functional impact of one of the Nationally Consistent Collection of Data's (NCDD) four broad disability categories: physical, cognitive, sensory, or social/emotional • RAR (reasonable adjustments resourcing) targets resources to all disabilities including dyslexia, attention deficit hyperactivity disorder (ADHD), mental health conditions and foetal alcohol spectrum disorder, as well as autism, intellectual disability, and vision, hearing, and physical impairments • RAR policy aims to provide resources to schools to enable them to make reasonable adjustments for students with disability to support them to access and participate in education on the same basis as their peers • Enrolments in the top three NCCD adjustment levels allow schools to employ additional teachers and teacher aides.

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Territory	ACT Education Directorate	Inclusive Education for Children and Young People with Disability in ACT Public Schools (information paper)	2021	✓	✓	• Small group programs provided at ACT public schools, including learning support centres, learning support units, learning support units - autism, P-10 school disability program. These programs are available for students with disability and/or autistic students. • Inclusion focuses on supporting education professionals to meet the diverse needs of every student in ACT classrooms and ensuring that students with disabilities and their families are included in a way which suits them • The Future of Education also includes continued growth in teachers' skills (professional learning) and confidence, as well as strengthened partnerships between schools and across agencies • Infrastructure improvements are underpinned by principles of universal learning. This supports inclusion of students with disability • Student Resource Allocation was developed to implement a student needs-based school funding model for ACT public schools. This aims to ensure that all students with disability benefit from adjustments required to successfully participate in learning • Students with disability should feel supported within a culturally safe school environment • All ACT school are required to: (a) consult with parents to understand their child's educational needs and the adjustments required to support the student; (b) apply reasonable adjustments to enable students with disability to take part in education on the same basis as other students; (c) assist students and families to feel safe and supported in the education environment.

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Territory	ACT Government Education	Strengthening Inclusive Education in ACT Public Schools	N/A	×	✓	• Not all students feel included and welcomed at school or have a learning program that best meets their needs. It is recognised the need to continue to build capability for inclusive practice - and that appropriate adjustments, for example, organisation, curriculum, physical environment, teaching, and inclusive strategies - help to make schools inclusive. “We are laying the foundation for reform recognising that strengthening inclusion will take time, commitment, resourcing, and intentional planning.” • Since 2015, the ACT Education has progressed significant reforms, consultations, and responses, ‘we have consistently heard that students with disability and their families want: (a) School communities to celebrate and welcome their school’s diversity and to be aware of the needs of students with disability and how those needs should be met; (b) Adequate resourcing provided to schools to support students with disability, especially in relation to the numbers of support staff working directly with children; (c) Teachers and other staff at schools to have the capability to accurately assess the subtle and complex nature of student support needs and develop and evaluate education programs which are matched to student need; (d) A clear policy intent and definition of inclusion where all students can be included in their local school, including infrastructure that supports access and participation for all students; (e) Specialist schools providing expertise and partnering with mainstream schools in education (e.g., dual enrolment) and activities (e.g., excursions, camps); (f) Strong partnerships between schools and families of students with disability to enable a lasting and positive impact on performance for all parties.’

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Territory	ACT Government Education	Strengthening Inclusive Education in ACT Public Schools: Discussion paper	2022	×	✓	• Seven aims for achieving greater inclusion • Culture, including: (a) Understanding the impact of language and the importance of shared, strengths-based language; (b) Sharing responsibility - collaborative decision making, commitment and communication • Workforce, including: (a) Defining more specialist skills and access to related expertise (e.g., knowledge in assistive technology and complex behaviours); (b) Different roles to support diverse needs (e.g., Learning Support Assistants (LSAs), Disability Education Coordinators (DECOs), Allied Health) • Relationships, including: (a) Increasing awareness of 'hidden' disability including mental health and language disorder; (b) Mechanisms to strengthen the response to parent/carer feedback; (c) Investigating new ways to collaborate with the NDIS • Learning, including: (a) Further strengthen the confidence of all teachers to collaboratively develop, implement, revise, and report against flexible learning plans, strategies, and goals throughout the school year; (b) Supporting schools and teachers to be flexible in delivery of education to ensure access for students with diverse needs • Key transitions, including: (a) Planning collaboratively and ensuring student agency throughout all transitions; (b) Strengthening the structured and coordinated transition approaches, ensuring timely communication with students and families • Resourcing, including: (a) Moving the resourcing narrative from deficit or problem based to needs and strengths based; (b) Enabling opportunities to be creative and deliver education flexibly to meet diverse learning needs • Infrastructure, including: (a) Planning for, designing and building new local schools that offer flexible and adjustable educational approaches; (b) Universal design principles to meet the needs of all learnings, including in planning upgrades and maintenance of existing schools.

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Territory	ACT Government Education	Students with a Disability Meeting their Educational Needs Policy	2022	×	✓	• The Education Directorate (the Directorate) supports and complies with the requirements of the Disability Discrimination Act 1991 and the Disability Standards for Education 2005 • ACT public schools provide educational programs and make reasonable adjustments for students with disability at the time of enrolment and during the course of their education, ensuring they are able to access and participate in education on the same basis as other students.
Territory	ACT Government Education	Students with a Disability Meeting their Educational Needs Procedure and Hydrotherapy Pools Procedure	2022	×	✓	• ACT public schools will: (a) Establish a team to monitor the educational progress of students with disability, identify and coordinate the support mechanisms required to meet the educational, pastoral care, safety and health needs and coordinate their planning and review processes; (b) Provide information about programs and procedures to parents, actively encourage their participation and work in partnership with families; (c) Involve students and parents in the Individual Learning Plan process as students move through their schooling; (d) Ensure all students receiving disability education services have an annual Disability Education Program Review meeting; (e) Ensure staff understand and address their obligations under the policy, procedures and relevant legislation; (f) Ensure staff have appropriate skills and relevant training to work with students with disability • Every student accessing support under the ACT Student Disability Criteria or who is supported with additional resources or services must have a current Individual Learning Plan (ILP) • The teacher with the major responsibility for coordinating and/or delivering the student's educational program also has responsibility for coordinating the development of the ILP in collaboration with the student and parents and ensuring it is reviewed, at a minimum, on an annual basis • The ILP is reviewed through the annual Disability Education Program Review process. • An annual Disability Education Program Review meeting is required for each student with disability, as defined in the ACT Student Disability Criteria, or who is supported with additional resources or services from the Directorate. The meeting formally reviews progress against the goals and priorities identified in the ILP and reviews the ongoing appropriateness of the current placement.

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State	NSW Department of Education	Inclusive Education Statement for Students with Disability	N/A	×	✓	• Student Agency and Determination: (a) Students have a voice, and are supported to express their views; (b) Students are involved in decisions that affect them; (c) Teachers and school leaders develop individualised learning goals that set high aspirations for students with ongoing review • Parent and carer inclusion: (a) Teachers and schools work in partnership with the student's parents/carers and support people to achieve the best outcomes for their child's education; (b) Teachers and schools will continue to seek the views of parents/carers to determine the most appropriate education program for students to ensure it continues to achieve the best learning and well-being outcomes possible • Social and Cultural Inclusion: (a) Leaders in schools and those supporting schools model inclusion in all aspects of their work • Curriculum Inclusion: (a) Students with disability are supported to access the same curriculum and syllabus outcomes as their peers, in developmentally appropriate ways. Critical to this is student-centred education planning, reasonable adjustments and differentiated teaching, learning and assessment activities; (b) Teachers use evidence-based practices that address the diverse needs of students in their classes; (c) Teachers and school leaders work in partnership with a range of services to provide personalised support. This includes allied health workers, other government agencies, specialists, and the community to meet the needs of students at school.

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State	NSW Department of Education	Disability Strategy: A living document improving the outcomes for children and young people, and their families	N/A	✓	✓	• The NSW Auditor-General reported that teachers felt they lacked expertise and wanted greater support to help manage student behaviour, and to better support students on the autism spectrum and mental health needs. It is a signal that we need to further expand our range of high-quality professional development opportunities - particularly with respect to those students • 'We will invest in research to better understand the prevalence of autism and mental health in our schools' • In 2017, 33% of students supported in funded programs were autistic • In consultation with educators, disability experts and families, carers and many others, we have sought to identify what success looks like. A more inclusive education system is one where: (a) Students with disability are learning to their fullest capability; (b) Parents and carers are treated like partners in their child's education; (c) Teachers possess the necessary skills to effectively educate children with disability, and feel confident doing so; (d) School leaders wholeheartedly support and enable inclusive education practices; (e) Specialists work alongside teachers, providing support and guidance • Compared to 1% overall annual enrolment growth in NSW public schools, 'we're seeing 4% growth in students receiving targeted individual support' • Currently, only 9% of NSW teachers are approved to teach special education, and the number of new special education graduates each year is going down, not up • Currently, there is little consensus on how to measure learning outcomes for students with disability. As a result, these is very little research that robustly compares the results of children with similar needs across settings and practice. This makes it difficult to confidently identify and scale the approaches that work best for children and young people • Four step plan: (1) Strengthen support, including a suite of core, advanced and specialist professional learning; (2) Increase resources and funding; (3) Involve the family, including providing new resources for local use to educate school and local communities about disability; (4) Track outcomes, including of all students with disability.

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State	NSW Department of Education	Inclusive Education: Inclusive, Engaging and Respectful Schools	N/A	✕	✓	• All staff must: (a) Implement reasonable adjustments for students with disability to support them to enrol and participate in all aspects of school life, on the same basis as students without disability; (b) Consult students, or their parents or carers on reasonable adjustments; (c) Support students with disability to access the curriculum through reasonable adjustments, and personalised support; (d) Contribute to an education environment free from harassment and unlawful discrimination on the basis of disability. They must develop and implement strategies to prevent harassment and victimisation of students with disability; (e) Work in partnership with students, parents and carers, external service providers, and the community, to achieve the best outcomes for students with disability; (f) Support students, parents and carers with key transition points; (g) Model inclusive practice to promote social and cultural inclusion of students with disability; (h) Participate in professional learning about supporting the inclusion of students with disability.
State	NSW Department of Education	Inclusive Education for Students with Disability: Our policy	N/A	✕	✓	• This policy is about making public schools in NSW inclusive for students with disability. Students with disability should be able to go to their local public school. Students with disability should be: welcomed and included in all areas of school life. Students with disability should be able to learn in classes with other students. Students with disability should get support to: share their thoughts, ideas and opinions; set goals; speak up about what they want or need; learn with other students. • What happens in inclusive schools (e.g., buildings are accessible) • The rights of students with disability (e.g., Australia is a signatory to the UN Convention on the Rights of Persons with Disabilities). • The responsibilities of Principals in relation to students with disability (e.g., they must talk to students, their families and other support people; they must have a complaint system that is accessible to students and their families) • The responsibilities of other staff members including teachers (e.g., they must “change how they teach to meet the needs of students with disability”), Department of Education staff and support staff (e.g., they “must help teachers to make their classrooms and learning spaces inclusive”).

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State	The Government of Western Australia, Department of Education	Public Education - A world of opportunities: Disability access and inclusion plan 2018-2023	2017	✓	✓	• Specialist learning programs for the specific needs of students on the autism spectrum who have very complex support needs started in 2017 and will be located in 16 mainstream primary and secondary schools by 2020 • Some Principals, teachers and education assistants received professional learning including TEACCH programs for students on the autism spectrum; Alternative and Augmentative Communication; and Communication and Oral Language • Strategies provided for the eight key outcomes. People with disability: (1) Have the same opportunities as other people to access the services of, and any events organised by, the Department of Education; (2) Have the same opportunities as other people to access buildings, and other facilities of the Department of Education; (3) Receive information from the Department of Education in a format that will enable them to access the information as readily as other people are able to access it; (4) Receive the same level and quality of service from the staff of the Department of Education as other people receive from the staff of the Department of Education; (5) Have the same opportunities as other people to make complaints to the Department of Education; (6)H ave the same opportunities as other people to participate in any public consultation by the Department of Education; (7) Have the same opportunities as other people to obtain and maintain employment with the Department of Education; (8) Learning outcomes are improved for students with disability.
State	The Government of Western Australia, Department of Education	Equity and Inclusion Charter: People and services committee	2017	×	✓	• To ensure policies are inclusive, fair and responsive, the following factors are to be considered when developing, reviewing and revising Departmental policy: policy impact; policy adjustments or remedies; policy requirements; and students. In relation to students. this will consider whether the policy assists the Department to provide high quality teaching and learning for every child – whatever their ability, wherever they live and whatever their background. As part of this, the learning environment for students with disability will be considered.

Organisation level	Organisation name	Policy name	Policy date	Reference to autism	Reference to disability	Relevant information
State	The Government of Western Australia, Department of Education	Enrolment Framework for Students with Disability in Public Schools	2022	✓	✓	• Specialist learning programs for eligible students on the autism spectrum include: (a) The primary Specialist Learning Program for Students on the autism spectrum at identified primary schools.; (b) The secondary Specialist Learning Program for Students on the autism spectrum at identified secondary schools; and (c) The early intensive intervention program or Kindergarten and Pre-primary students on the autism spectrum at identified education support centres • The Principal managing a specialist learning program for students on the autism spectrum will: (a) Accept applications for the program from students on the autism spectrum who reside within and outside the school's local intake area; (b) Confirm a student meets the enrolment criteria for the program; (c) Prioritise applications according to the enrolment criteria for the program; (d) Offer kindergarten enrolment subject to the immunisation requirements; (e) Apply proximity of a student's usual place of residence to the school where the number of prioritised applications exceeds the places available; (f) Enrol eligible students; and (g) For a student who exits the program, facilitate the transfer and transition to a new school where this is agreed to by the parents • Guidance Enrolment criteria for specialist learning programs for students on the autism spectrum are: (a) A diagnosis of autism without accompanying intellectual disability; (b) The capacity to work at or near the academic standard for the student's year level; (c) Social, emotional and/or behavioural issues and challenges that are directly attributable to the impact of autism; (d) Self-management of personal care requirements. Principals may decline to enrol eligible students if the specialist learning program does not have available capacity • The WA Education provision for students with disability includes: (a) Local schools with appropriate teaching and learning adjustments; (b) Local schools with access to specialist disability support services; (c) Specialist programs in identified schools for eligible students on the autism spectrum; (d) Endorsed specialist programs in identified schools for eligible students who are deaf or hard of hearing; (e) Specialist education support programs for eligible students with disability in education support schools, education support centres and identified schools with an endorsed education support program; (f) Language development centres for eligible students with speech and language impairment.

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State	Government of South Australia	Inclusive SA: State Disability Inclusion Plan 2019 - 2023	2019	✗	✓	• State education and training sectors to support inclusive education culture and practices • State education authorities to work in partnership with children, students, parents or carers, industries and the community to provide curriculum and learning opportunities that are personalised and tailored to the individual, and prepare for life beyond school • Determine data required to measure and track the percentage of people living with disability participating and achieving in education and training.
State	Government of South Australia, Department for Education	Children and Students with Disability Policy	2023	✓	✓	• Autism intervention programs available as part of an inclusive education system • The Department is committed to inclusion, taking reasonable steps to ensure that children and students with disability can attend their local preschool, children's centre or school, on the same basis as a child or student without disability, without experiencing discrimination • The standard establishes the need for access to be granted that is reasonable and in effect provides the same access for children and students without disability once any reasonable adjustments have been made or can be made • As a provider of education services, the Department is required to take all reasonable steps to ensure any course, program or service is designed in such a way that it can be modified to enable a child or student with a disability to participate • Any child or student with a disability must be granted access to support services offered to other children or students on the same basis and without discrimination • The standards require education providers establish the necessary policy, procedure and environment that enables children and students with disability to engage in their approved learning program free from harassment and victimisation • Principals should: Develop, implement, monitor and review the One Plan (or related documents) for any child or student with a verified disability at their site • Teachers should: Develop, implement, monitor and review the approved learning program of all children and students, including those with disability.

Organisation level	Organisation name	Policy name	Policy date	Reference to autism	Reference to disability	Relevant information
State	Government of South Australia, Department for Education	Principles of Inclusion for Children and Students with Disability in Education and Care	2022	×	✓	• All children and students who experience disability have the right to access and participate in education • All children and students who experience disability have the ability to learn and the right to exercise their voice, choice, and control in managing their own educational experiences • All children and students who experience disability have the right to develop to their fullest potential and to be active, valued citizens in the community • Teachers, early childhood education and care centre and school communities and the parents/carers/advocates of children and students who experience disability have the responsibility for taking action for inclusive behaviour in their education and care setting • All children and students who experience disability have the right to an appropriate and adequate allocation of resources to enable their right to access and participate meaningfully in education • All children and students who experience disability, their parents/carers/advocates, teachers, and members of the early childhood education and care centre and school communities have the right to be safe - physically, emotionally, culturally and socially and to be treated respectfully • All children and students who experience disability, their parents/carers/advocates, teachers and members of the school community have the responsibility to operate within the legal framework provided by the Australian and South Australian governments.

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Territory	Northern Territory Government, Department of Education	Inclusive Education for all Children and Students: Framework for inclusion 2019-2029	2019	×	✓	• The Framework focuses on: (a) Ensuring that all children and students can access an education and contribute to their community; (b) Affirming children's rights to education, safety and well-being under the Disability Discrimination Act 1992, the Disability Standards for Education 2005 and the United Nations Convention on the Rights of the Child; and (c) Developing individual strengths, with high and appropriate expectations for each and every child and student • The government will: (a) Empower and encourage families to be more actively involved in decision-making about their children's education by listening to the voices of children and families and providing accurate and timely information about the options available for their children; (b) Explore service delivery approaches to inclusion that involve mainstream schools, specialist schools and external specialist agencies; and (c) Develop programs and integrated approaches that help schools and early learning centres support all children and students, to reach their potential.
Territory	Northern Territory Government, Department of Education	Review of Policy and Practice for Students with Additional Needs	2018	✓	✓	• Autism spectrum programs provide an educational program for students in a mainstream primary school setting who have a diagnosis of autism. The programs provide explicit interventions and strategies for students to develop social understandings and contextually appropriate skills and behaviours to achieve educational potential. These programs are designed as short-term and intensive, utilising evidenced based pedagogies to support students in the domains of Communication, Social interaction, Restrictive Interests and Repetitive Behaviours, Sensory Processing and Learning Styles • Commitment to equipping government schools with the resources required to meet the needs of students with additional needs, including staff skills. As such, it offers to school staff a suite of special education courses online including understanding autism • Strong interest from respondents in both mainstream schools and special schools in working together more closely to enhance outcomes for students. Most saw special settings such as autism spectrum units and satellite classes as a key means to achieve this outcome • Three key elements emerged as the basis for a framework that will guide the development and implementation of appropriate education supports for students with additional needs: (1) Strengthening shared decision making; (2) Improving professional practice (3) Enhancing and evidence-led system. Strategies to achieve this are discussed in the document.

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State	Tasmanian Government	Accessible Island: Tasmania's disability framework for action 2018 - 2021	2018	✓	✓	• The Department provides specialist services including Autism Consultants • Support all people to access, participate and engage in learning and employment opportunities. 'We aspire to create a culture of high expectations and high achievement in the provision of quality inclusive and accessible education environments for people with disability.' • Government will continue to: (a) Ensure that individual student accessibility issues are prioritised and the required works are completed within the annual capital and minor works programs; (b) Work collaboratively with school staff to map student pathways from Kindergarten to Year 12 and pre-plan required access provisions in advance of student commencement, where known • Government will: (a) Ensure all Department of Education staff work collaboratively to provide high quality inclusive and supportive learning opportunities for students with disability; (b) Promote the Disability Standards for Education 2005 and set clear expectations that Department of Education staff are required to meet their obligations by ensuring that students with disability can access and participate in education on the same basis as other students.
State	Education Victoria	Students with Disability	2021	×	✓	• The Department is committed to embedding inclusive education in all school environments for students with disability and additional needs • Inclusive Education: (a) Ensures that students with disability are not discriminated against and are accommodated to participate in education on the same basis as their peers; (b) Acknowledges and responds to the diverse needs, identities and strengths of all students; (c) Occurs when students with disability and additional needs are treated with respect and are involved in making decisions about their education; (d) Benefits students of all abilities in the classroom and fosters positive cultural change in attitudes and beliefs about disability, in and beyond the school environment; (e) Contributes to positive learning, engagement and well-being outcomes for students • Reasonable adjustments: When planning an adjustment for a student, the school should consult with the parent or carer(s) and the student, through the Student Support Group process. This process should apply to all students with disability or additional needs, not just those who are eligible for support under targeted funding programs.

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State	Victoria State Government, Education and Training	Victorian Autism Education Strategy	N/A	✓	×	• Framework for Improving Student Outcomes (FISO 2.0) includes six pillars: (a) Promote and celebrate autism inclusion and diversity at the whole school level; (b) Build the capacity of school leaders and staff to meet the educational needs of autistic students; (c) Involve the student, families and experts in collaboratively planning for students' education; (d) Support autistic students' health and well-being; (e) Support autistic students' individual education needs; and (f) Strengthen accountability and transparency for students with disability • Autistic students: (a) Are less likely to finish Year 12 than other students; (b) Often change schools to get their needs met; (c) Can be more likely to disengage from school • Autistic students are more likely to experience: (a) Communication and social differences; (b) Mental health challenges; (c) Learning difficulties; (d) Other conditions (i.e., intellectual disability, motor difficulties, epilepsy).

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State	Victoria State Government, Education and Training	Inclusive Education for all Students with Disabilities and Additional Needs: The government's response to the review of the program for students with disabilities	2016	✓	✓	• The government recommends: (1) Developing a clear inclusive education policy and framework; (2) Developing an Inclusive Schooling index that enables school to self-assess inclusivity; (3) Developing an Inclusive Education Workforce Capability Strategy to better assess professional learning so students with disability are fully supported; (4) Rolling out existing professional learning relevant to disability; (5) Assisting with capacity development; (6) Considering how to harness new regional reforms to better access knowledge in each local area; (7) Developing options to support specialist schools to become "centres of expertise"; (8) Providing guidance on how Education Support staff can be used to support academic and behavioural outcomes of students with disabilities; (9) Developing collaborative approach to supporting students with disabilities; (10) Developing guidelines on personalise learning and support plans; (11) Developing tool that identifies students' strengths and functional needs; (12) Implementing stronger system of accountability for outcomes of students with disabilities; (13) Providing interim funding for students transitioning from Year 6; (14) New funding model based on functional needs; (15) Improved access to support and expertise to meet the learning and support needs of students on the autism spectrum; (16) Provide additional funding to better support the needs of students with learning disabilities and autism; (17) Roll out of special needs plan; (18) Investigate early years screening for learning disorders; (19) Raise awareness and encourage support around dyslexia; (20) Implement a dyslexia and learning difficulties strategy; (21) Develop tiered funding model based on strengths-based functional needs approach; (22) Develop relationship with NDIA to ensure maximum alignment with NDIS as it evolves; (23) Develop strengths based functional needs approach to assessing student need; (24) Sufficient resources from department to implement the above recommendations; (25) Undertake regular consultation with education sector and community to inform development of reforms.

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State	Victoria State Government, Education and Training	Supported Inclusion Schools	2021	✓	✓	• Schools can access Department resources including teaching and support resources to create autism-friendly environments for students and families • The Program for Students with Disabilities is a supplementary funding program that provides resources to schools to support the provision of education for a defined population of students with disabilities, including autistic students • Supported inclusion school model has two short-term objectives: (1) Increase opportunities for students with disability to attend a school closer to home, study alongside mainstream students and access specialist infrastructure and teaching expertise; (2) Respond to a growing demand for education options across Victoria, particularly for students with disabilities • Each student with a disability should have a Student Support Group comprising of the Principal (or nominee), the classroom teacher (in a primary school) or year level or well-being coordinator (in a secondary school), the parent/guardian/carer and, where appropriate, other education or health and well-being professionals. Students themselves should also be involved, as appropriate. • Each student with a disability must have an Individual Education Plan developed with their Student Support Group that sets out their long and short-term learning goals • All students require support when transitioning from primary school to secondary school and from secondary school to post-school options. Students with disabilities may need more intensive support and more time to prepare. The level of support and planning required may differ depending on the nature and severity of the student's disability. During transition, there should be strong collaboration with families, joint planning between schools, proactive planning for post-school pathways. • Supported Inclusion Schools should: (a) Ensure that students begin career planning early and are supported by their career's advisers, Student Support Group, Careers Coordinators, National Disability Insurance Agency planners, and other staff; (b) Provide students (including those with disability) with a variety of workplace learning opportunities

Organisation level	Organisation name	Policy name	Policy date	Reference to autism	Reference to disability	Relevant information
						• Supported Inclusion Schools will provide students with disabilities enhanced support to attend mainstream education classes (where appropriate) and receive additional support in specialised facilities including areas designed for targeted teaching and therapies. These schools build the capabilities of staff to respond to the diverse needs of their students, through appropriate curricula, organisational arrangements, teaching strategies, resource use and partnerships with their communities. The spaces are designed to support specific learning needs, with acoustics, lighting, resource access and physical comfort factors designed to address the needs of students with disability.

3.3.4 Research evidence and policy/guideline gap analysis

In addition to the specific research gaps, there are gaps between what is discussed in the research and what is recommended in policy. Some examples of these gaps are highlighted below.

- Multiple policies and documents state the aim of providing high-quality education so as to support autistic children to develop to their fullest potential. Multiple policies also state the rights for all children to access and participate in education, with some states/territories specifically stating the right for inclusive education. However, the research review suggest that not all teachers feel confident or competent at supporting autistic students in their classroom, and concerningly, not all Australian teachers have positive attitudes towards supporting autistic students in inclusive settings
- Teacher knowledge and understanding of inclusion and/or autism is highlighted as a key area of action for multiple jurisdictions. The findings within the umbrella review strongly support improving teacher knowledge as a critical action, but research is needed to identify the best way to improve knowledge so that it also improves practice
- The research highlighted that educational professionals may have limited knowledge of how autism may present differently based on child characteristics, for example, in female students, in students who come from culturally or linguistically diverse families, or in students with different cognitive levels. Despite this being highlighted in the research as important for students, ensuring teacher understanding of such intersectionality is not explicitly addressed in policy
- Policies recommend that educational spaces should be designed to be supportive of the range of sensory profiles of the student population. However, there is little research which looks at evidence-based ways to teach professionals to create sensory-considerate spaces
- The majority of the autism-focussed research in education has taken place outside of Australia. Therefore, further funding for the research and implementation of resources is needed for these policies to be fully enacted.

3.3.5 Umbrella review: Postsecondary education

An umbrella review is a form of research that brings together the findings of all existing reviews (systematic and scoping) that report on a specific topic. The focus of this review was on a range of factors related to postsecondary education for autistic students. The terms used for the searches, and the number of articles identified, screened, and included, are provided in Appendix F-1 and Appendix F-2. The final umbrella review reports on 20 systematic reviews, four of which were led by Australian authors. All 20 of the systematic reviews were written in the last 9 years. The 20 systematic reviews collectively report on 341 individual studies.

The information and findings from the included reviews are summarised in the subsections below. When reporting on the number of people or participants in the review, this will be represented as n = [number of participants]. When reporting on the number of reviews that considered a topic, this will be represented as k = [number of reviews].

3.3.5.1 Participants within included reviews

In total, the reviews included over 206,098 participants (of which over 4,835 were autistic), with sample sizes for individual studies ranging from 1 to 154,837 (three reviews did not provide sample sizes). Only seven systematic reviews provided information on the gender of the participants. Most of the participants in these seven reviews were male (the average percentage reported ranged from 59% to 83%). Participants, or the case studies reported, ranged in age from 15 to 70+ years.

3.3.5.2 Quality of included reviews

The quality of the included systematic reviews was assessed using the JBI Critical Appraisal Tool for Systematic Reviews. This tool assesses the methodological quality of a systematic review. The maximum score is 33, which indicates a very high-quality systematic review. The average quality score for the 20 included systematic reviews was 22.35 (67.73%), with the quality score ranging from 11 to 30.

3.3.5.3 Topics of included reviews

The 20 reviews identified in the area of postsecondary education for autistic students can be summarised across three key topics. These were interventions, programs, and supports for autistic postsecondary students (*k* = 17 reviews); experiences of autistic postsecondary students and their support networks (e.g., family) (*k* = 11); and online learning environments and educational technology for autistic postsecondary students (*k* = 1). Some reviews discussed more than one topic. The key findings for each topic are presented in Table 20.

3.3.5.4 Research gaps

After reading the 20 reviews, the research team identified a number of key research gaps. These are combined with the relevant research gaps noted within the reviews themselves, and summarised in Table 20.

In brief, there is a need for more quantitative studies of postsecondary education experiences, interventions, and supports that include objective and thorough evaluation measures. Furthermore, there is a lack of research that investigates the effectiveness and impact of interventions, supports, and programs (such as peer mentoring programs) on autistic students' outcomes relating to academic and personal changes. Additionally, there is a significant gap in the research pertaining to online learning environments and educational technology for autistic postsecondary students.

Aside from academic needs, the research highlighted that many autistic students may have support needs for non-academic areas, including mental health, social skills, and sensory needs. There was little empirical evidence in the reviewed research on the efficacy of mental health interventions for autistic postsecondary students and whether mentoring programs can significantly improve the outcomes for autistic university students who have related mental health conditions. There was also a lack of reported interventions for sensory sensitivities in the reviewed studies, though many students with ASD have indicated this is a concern.

Most of the systematic reviews (85%; 17 out of 20) focused on researching interventions, programs, and supports for autistic postsecondary students. The most identified intervention, peer mentorship programs, was explored in the literature through the lens of helping autistic students to adapt to postsecondary institutions. However, there is a clear need for research into how institutions should be (or are) adapting to suit the needs of autistic students. Additionally, there was limited research in the umbrella review that used longitudinal methods to evaluate the long-term effectiveness of interventions for autistic postsecondary students. Such research is needed to ensure educational adjustments and interventions support the students' preferred career trajectories. More research conducted over a series of months and years is necessary, as is the use of rigorous pre-post measures to evaluate the impact of interventions on student experience and outcomes. Such evidence in this field could be used to inform universities' use of evidence-based, effective interventions for autistic postsecondary students.

Overall, the research on autistic postsecondary students lacks inclusion of diverse populations in relation to gender, sexual identity, and language backgrounds. That is, most research involved students who identify as Caucasian, male, heterosexual, and English-speaking. Furthermore, few studies analysed a specific academic support despite many autistic students indicating they prefer these supports and that they find them useful. This may highlight the need for participant preferences to be given more consideration when designing supports for postsecondary students.

Table 20: Umbrella review findings for postsecondary education

Topic	Number of reviews on topic; citations	Key findings	Key research gaps identified
Interventions, programs, and supports for autistic postsecondary students	k = 17 (Dallas et al., 2015) (Morris et al., 2022) (Anderson et al., 2017) (Nachman, 2020) (Flegenheimer & Scherf, 2022) (Furuhashi, 2021) (Anderson et al., 2019) (Nguyen et al., 2020) (Paskins et al., 2018) (Kuder et al., 2021) (Stark & Lindo, 2022) (Duerksen et al., 2021) (Gelbar et al., 2014) (Widman & Lopez-Reyna, 2020) (Zeedyk et al., 2016) (Davis et al., 2021) (Kuder & Accardo, 2018)	• Frequently reported interventions include: • Academic: eliminate discomforting sensory stimuli, priority in choosing seats, exam supports (e.g., private room, extra time, permission to wear earplugs), note taking accommodations (e.g., use of laptops, recorded lectures, lecture notes, use of a note taker), organizational supports (e.g., color-coded binders/folders, calendar/organiser, alarms/reminders), group work facilitation, tutor, extended deadlines, coursework/curriculum modifications, early registration, reduced course load, calculator, and frequent breaks • Non-academic: Peer mentoring was the most reported non-academic support. Other non-academic supports included: • mentorship, group therapy, video self-modelling, cognitive behaviour therapy (CBT), peer support, biofeedback, skill building, transition facilitation and programs, social skills support, self-advocacy skills support, counselling, parent involvement, problem solving skills lesson, (cognitive) behavioural interventions, social support group, social stories, disability teams, communication support, and emotion regulation supports • Course waivers and course substitutions were suggested as being potentially helpful for autistic postsecondary students • The majority of autistic postsecondary participants were satisfied with the interventions; however, responses differed within and between interventions, making it difficult to draw general conclusions • Peer mentoring programs provide individualised support for students' needs. Generally, positive outcomes were reported in various domains such as social skills, academic performance, and sense of belonging • Interventions largely focused on social skills • Interventions generally had high reported satisfaction rates • Supports were often incongruous with needs and produced idiosyncratic benefits	• Need for individualised interventions and novel solutions for autistic postsecondary students and high-quality evaluations of these programs • Studies often rely on (subjective) participant feedback, with little integration of objective measures • Lack of research on evaluation of outcomes relevant to academic success or long-term independence • Lack of research on family/parental support and family involvement in postsecondary settings • Lack of supports around career objectives/ development, learning about job interests, and trajectories/pathways to college • Limited research examining how stress is addressed • Parents identified a need for transition services • Need for academic institutions to provide psychological supports for autistic postsecondary students • Lack of research on academic and faculty supports • Most postsecondary institutions provide traditional academic supports while non-academic supports and resources are often inadequate • Lack of research investigating the effectiveness of programs, supports, and interventions, especially on the effectiveness of peer mentoring programs and the impact they have on student outcomes (academic and non-academic) • Lack of cooperation between support services such as university disability services, counselling centres, students, and families

Topic	Number of reviews on topic; citations	Key findings	Key research gaps identified
Experience of autistic postsecondary students and their support networks (e.g., family)	k = 11 (Adams et al., 2019) (Dallas et al., 2015) (Widman & Lopez-Reyna, 2020) (Toor et al., 2016)* (Nuske et al., 2019) (Flegenheimer & Scherf, 2022) (Anderson et al., 2017) (Kuder et al., 2021) (Davis et al., 2021) (Gelbar et al., 2014) (Nguyen et al., 2020) *note: only this one review focused solely on experiences; 9 also included interventions and one article focused on experiences and online learning	• Challenges related to experiences of autistic students (and their support networks) included: • Autism-specific challenges • Self-disclosure and awareness • Mental health and well-being • Autistic students reported to experience social, emotional, communication, and sensory difficulties which impact all aspects of their postsecondary education • Over 50% of autistic postsecondary students experience a mental health condition. Autistic postsecondary students reported significantly more mental health difficulties than non-autistic students, which they report as having a significant effect on their success in university, both academically and socially • Anxiety is the most commonly reported experience of postsecondary autistic students, followed by loneliness and depression • Autistic postsecondary students often feel prepared academically but have difficulties with daily living and social skills • Some students experience isolation/marginalisation (e.g., peer rejection), tiredness, overwhelmed, as well as housing and roommate concerns • Poor self-advocacy skills make it difficult for autistic postsecondary students to access available supports	• Research needs to explore lack of awareness and understanding of autism among academic and professional staff in postsecondary education settings • Need to develop and evaluate proactive mental health interventions and services that are accessible to postsecondary students • Need to explore methods to support postsecondary autistic students' social inclusion and daily living skills • Research should explore methods for improving autistic students' self-advocacy skills, especially in relation to accessing the required supports
Online learning environments and educational technology for autistic postsecondary students	k = 1 (Adams et al., 2019)	• Only one systematic review focused on online learning for autistic postsecondary students. The review included four studies (three case studies) on this topic • In one study, almost half (47.4%) of the students (n = 19) who studied online preferred online compared to face-to-face study • In two case studies, the students reported that face-to-face learning provided clearer direction, which resulted in more confidence in the learning process as opposed to online learning • Online learning tools included discussion boards, learning management systems, library, Google advanced search, and email	• Lack of research that examines online learning environments and educational technologies for autistic postsecondary students • Impact of course design on autistic postsecondary students' needs further investigation

Note. *all other groups that have not been identified separately

3.3.6 Policy and guideline review: Postsecondary education

An overview of state and federal postsecondary education policy as it relates to autism and broader disability is provided below. Several combinations of the following search terms: “tertiary education”, “postsecondary education”, “training”, “vocational training”, “skills”, “university”, “autis/m/tic”, and “policy” were entered into state and federal education department pages to source key documents. A general search was also conducted, with the same search terms, to ensure all relevant documents were identified. Policies or guidelines were only included if they were current or had not yet been superseded. Note that for this review, organisational policies (e.g., of higher education providers) have not been included. Policies often identify the need for government employees who work alongside colleagues or customers/clients with disability to gain additional education in the support of people with disability, but this is not the focus of the review. Similarly, policies with specific reference to autism more commonly addressed early, primary, and secondary education, which have been addressed in the relevant sections of this report. This review does include some reference to transition from high school and to career supports at this stage of education but is primarily focused on education and training related to work readiness. It is important to note that policies written to address higher education (e.g., the NSW Higher Education and Tertiary Policy) do not refer to disability and inclusion. So, this policy review summarises federal and state disability plans or strategies where postsecondary education in mentioned.

None of the state level policies summarised below specifically refer to autism. Education and training, as a pathway to meaningful participation, is a key strategic priority within all mentioned disability strategies and plans (see Table 21). Only one policy initiative document identified in this review referred specifically to autism, being the Australian Government Response to the Select Committee on Autism (report): Services, support, and life outcomes for autistic Australians. This policy initiative considers key priority areas including improvement of education for autistic people as part of the development of the National Autism Strategy (this document). The policy document includes guidelines around meeting the needs of autistic students by increasing understanding among higher education staff, promoting autism-friendly campuses and information, and the adoption of autism inclusion and peer mentoring programs. Several postsecondary education providers have developed disability action plans and do have many initiatives to support a neurodiverse student body. For example, Curtin University Specialist Mentoring program is one of the first and largest peer support programs designed by, and for, autistic students. Similarly, TAFE and Apprenticeships Australia have also implemented disability action plans. For example, the Disability Australian Apprentice Wage Support aims to encourage employers to mentor people with disability during their apprenticeship. However, limited education provider policy specific to autistic students is likely influenced by the lack of autistic-specific policy and guidelines at the state and federal level.

Table 21: Policy and guideline review findings for postsecondary education

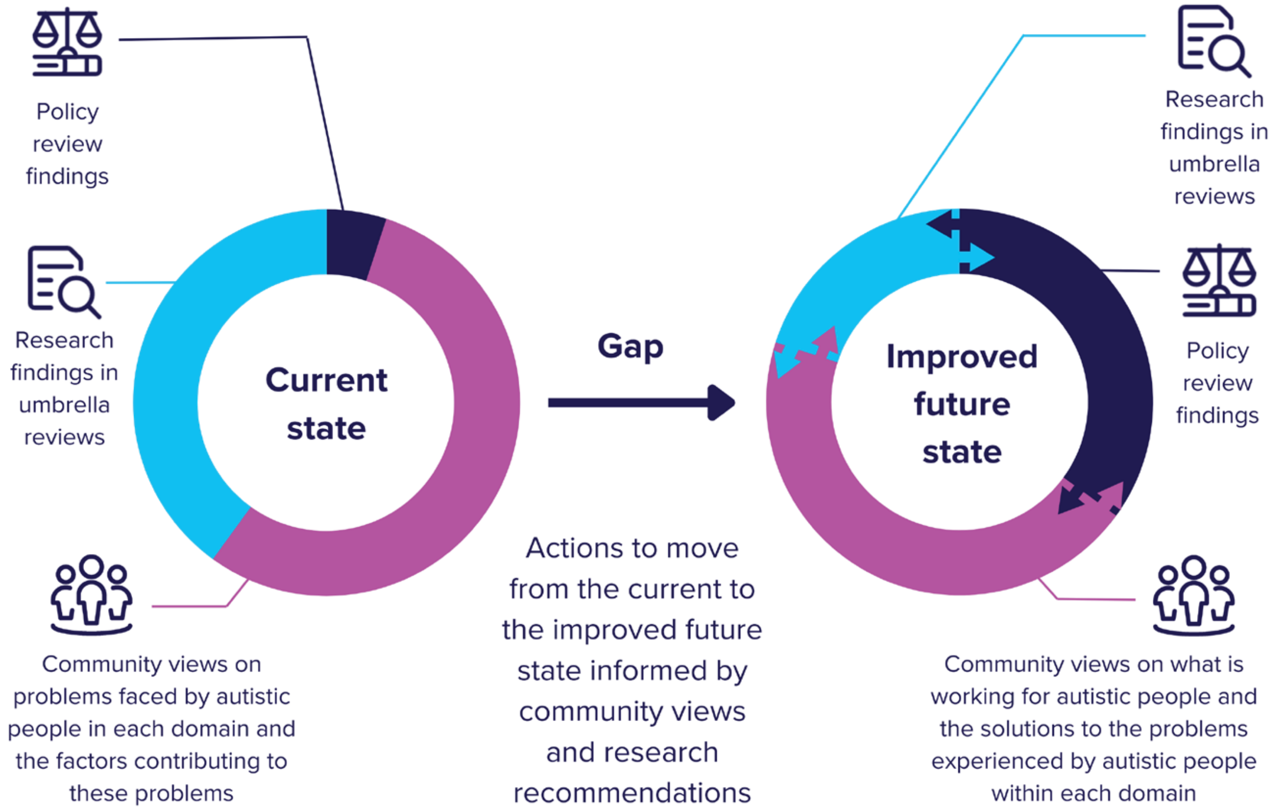
Organisation name	Policy name	Reference to autism	Reference to disability	Relevant information
Australian Government (Federal)	Australian Government response to the Select Committee on Autism (report): Services, support and life outcomes for autistic Australians 2022	✓	✓	• Apply an autism lens to ensure the Disability Standards for Education meet the needs of autistic students • The Equity in Higher Education Panel to include a specific focus on the needs of autistic students with increase in autism understanding among staff, autism-friendly campuses and information, and widespread adoption of autism inclusion and peer mentoring programs • For a transition to work road map to be developed to establish stronger links between school, universities, and employers and to embed evidence-based transition programs.
Australian Government (Federal)	Australia's Disability Strategy 2021-2031	×	✓	• An overall outcome for people with disability to achieve their full potential through education • Prioritises improvements to pathways and accessibility • Prioritises increased opportunity to participate in accessible and inclusive lifelong learning.
State Government (WA)	A Western Australia for Everyone; State Disability Strategy 2020 to 2030	×	✓	• Focus on strong pathways to work and economic participation via partnerships with students, industries, and community • Curriculum, skills development, and learning opportunities to be tailored to the diverse range of needs and that support their individual career aspirations.
State Government (SA)	Inclusive SA; State Disability Plan 2019 to 2023	×	✓	• Promote inclusive places of study that provide pathways to meaningful and inclusive employment and volunteering opportunities • State education and training sectors to support inclusive education culture and practice that are personalised • Data to measure percentage participation in education and training • Explore pathways from education and training settings to post learning opportunities.

Organisation name	Policy name	Reference to autism	Reference to disability	Relevant information
Territory Government (NT)	Northern Territory Disability Strategy 2022 to 2032 Northern Territory Disability Strategy Action Plan 2022 to 2025	×	✓	• Education to meet individual lifelong needs • Support school leavers transition to further education • Specific reference to Charles Darwin University Disability Inclusion Programs.
State Government (VIC)	Inclusive Victoria State Disability Plan (2022-2026)	×	✓	• Education to be accessible, inclusive, and linked to employment outcomes • To link industry engagement with school graduates for career pathways • Specific reference to TAFE disability inclusion strategy.
State Government (TAS)	Accessible Island Tasmania's Disability Framework for Action (2018-2021)	×	✓	• To support the transition from school into post-school education, training, or employment • Specific reference to TasTAFE compliance with Disability Standards for Education 2005 • Selection and enrolment procedures should not discriminate • Provision of specialist staff to coordinate support, comprehensive range of reasonable adjustments that lead to learning and assessments that are fair, flexible, valid, and reliable • Connect schools with post-school options • Grow flexible, high-quality, and innovative VET opportunities.
State Government (QLD)	All Abilities Queensland: Opportunities for All State Disability Plan (2017-2020)	×	✓	• Equal access to education and learning across all stages of life.

3.3.7 Community views, research evidence, and policy/guideline alignment and gap analysis

As well as the research gaps identified as part of the research landscape mapping, the gap analysis (see Figure 4 for process) allows comparison of the *current state* (predominantly based upon the community views survey analysis but also some findings of the umbrella review and policy review) to an *improved future state* (based upon community views around what is working well, policy review, and some umbrella review findings). Of note is that the umbrella review for primary and secondary education focussed on teacher knowledge, attitudes, and training.

Figure 4: Gap analysis: Current to improved future state



As few respondents in the community views survey commented specifically on postsecondary education, further work is needed to identify community and professional views on the experiences of autistic students in postsecondary education settings. This would include ideas on how best to support the needs of autistic students.

The gap analysis work for education highlighted the following elements that need to be addressed in order reduce the problems experienced by autistic people:

3.3.7.1 There is a need to improve the level of autism knowledge and understanding of professionals working in primary, secondary, and postsecondary educational settings

Current state

Almost one in three people who completed the education section of the **community** views survey highlighted that those working in educational settings (teachers, leaders, support staff) lack knowledge of autism (or broader neurodiversity), its presentation, and how it impacts learning or education. Of note is that this problem was reported by 37% of those working in educational settings (compared to 30% across the entire sample). The community views survey also identified a lack of understanding of autistic students' social preferences as a problem within educational settings and a focus on behaviour as something to be modified, rather than understood and supported.

The **research** review findings align with this. These indicate that teacher knowledge of autism significantly varies, and one review describes knowledge levels as "low to moderate". The reviews also indicate that teachers have even more limited knowledge of how autism presents in subgroups, such as females. Teacher training on autism was described as "inadequate" in one review. Little is known about the autism knowledge or autism training of postsecondary educators. The research review also highlights the importance of teacher knowledge of autism; autistic students report that their teachers' knowledge of autism impacts the quality of the education they receive.

Improved future state

The need for professional development (as a way to increase knowledge and capability of educators) on a range of disabilities is noted in federal and state/territory-based **policies** (e.g., Disability Standards for Education, 2005, "Inclusive Education for Children and Young People with Disability in ACT Public Schools", 2021). The NSW Disability Strategy specifically states the need for core, advanced, and specialist professional learning. There is a need for postsecondary policies to guide this area in these settings. The **community** views on what would reduce the problems that autistic people face in educational settings highlighted a need for pre-service and in-service training on autism, not only for the educators but for all staff working in schools (recommended by 41% of respondents). Additionally, there was a recommendation for broader initiatives which aim to increase educator and community acceptance of autism and tolerance of diversity, which would then have a positive impact on the understanding of autistic students' education.

Steps that can be taken to move from the current to the improved future state include:

- Co-development (i.e., developed collaboratively with autistic people) and co-delivery (i.e., delivered collaboratively with autistic people) of evidence-based autism-specific training that is relevant and accessible to all staff working in all educational settings. This could move people from understanding some behaviours or presentation of autistic students from that of disorder (therefore needing to be modified) to that of diversity or difference (which can be accepted and celebrated). This could be incorporated into teacher pre-service training as well as being part of standard onboarding training so that a baseline level of knowledge is held by all those in educational settings. The effectiveness of this could be supported by relevant federal and state policymakers suggesting or mandating completion of such training within policy. For postsecondary educators, there may need to be site-specific or institution-specific ways to deliver the training to educators

- Co-development and co-delivery of specialised training for professionals whose role would benefit from specific knowledge of autism; this would align with the tiered training approach noted in NSW policy
- Broader community initiatives which aim to promote understanding, acceptance and celebration of diversity. These can include media messaging, positive representations of autistic and neurodivergent people in the media, and system-wide (e.g., school, workplace) programs or interventions.

3.3.7.2 There is a need for sensory-considerate schools and educational settings

Current state

The **community** views survey highlighted how school or learning environments can be overwhelming for those with sensory processing challenges, and how this then impacts upon autistic students' ability to learn. This may be downstream from the community view that schools are set up for neurotypical students (and staff), and others not having knowledge or understanding of autism to reflect on the impact that such settings can have on autistic people. The **research** review for postsecondary education highlighted how autistic students' sensory difficulties impact all aspects of their postsecondary education.

Improved future state

Some **policies** (e.g., Strengthening Inclusive Education in ACT Public Schools, 2021) make specific reference to making adjustments to the physical environment to promote inclusion and ensure students feel welcome and included in their schools. Others (e.g., Victorian State Government "Support Inclusion Schools", 2021) specifically state that acoustics, lighting, and comfort factors of learning spaces need to be designed to support specific learning needs of students with disabilities.

The **community** survey responses suggested that schools should be designed to minimise sensory overwhelm, and offer spaces where autistic people feel safe and comfortable. The responses recognised a need for additional funding for such changes to be made. There was also a suggestion of active consultation with autistic people and employing more autistic staff, both of which would help to achieve the aim of reduced sensory input settings. The suggestions of schools having additional staff (or fewer students) and there being more collaboration, communication, and planning between educational staff, the autistic student, and their supporters, are also elements that could help to work towards the future state of reduced sensory input learning spaces.

Steps that can be taken to move from the current to the improved future state include:

- Guidance for schools (which includes input from state education departments) on how to provide sensory-supportive spaces for autistic students. This should include information on how to provide such spaces within each classroom, so that students do not necessarily have to leave the classroom and miss out on learning or social opportunities
- Information and resources to support those working in learning environments to conduct environmental audits, including noise and light levels. The resources can suggest accommodations/adjustments that can be made to adjust areas that may pose challenges for autistic people

- Explicit invitation and permission for autistic people to use sensory supports in school settings, should they feel this would be beneficial for them.
- Co-development of methods for autistic people within educational settings to provide insight into sensory supportive and non-supportive elements of their learning environment.

3.3.7.3 There is need for those working in educational settings (including postsecondary settings) to provide adjustments, accommodations, and supports (including adjustments to instructions and assessments) to enable autistic students to participate, learn, and belong

Current state

The definition of inclusive education used in many of the **policy** review documents describes an educational setting where all students can access and fully participate in learning, alongside their similar-aged peers, supported by reasonable adjustments and teaching strategies tailored to meet their individual needs. Almost a quarter of people who completed the **community** views survey highlighted that a lack of adjustments or accommodations for autistic students was a problem that autistic people face when accessing education. Additionally, many respondents noted that teachers do not use instructional methods, pedagogy, or assessment methods that take into account autistic learning profiles and needs.

The post-secondary **research** review highlighted that supports provided to autistic university students were often incongruous with needs and produced idiosyncratic benefits. This may explain some of the high dropout rates reported for autistic students in postsecondary settings. The research review also highlighted that when supports are available, they may not be effectively accessed by autistic individuals due to challenges with self-advocacy and anxiety.

Improved future state

The majority of state/territory **policies** explicitly state that students with a disability are entitled to reasonable adjustments. Some (e.g., NSW) state that they are "critical" to supporting students with disability to access the same curriculum and syllabus outcomes as their peers. Most noted that adjustments or accommodations need to be implemented in consultation with the autistic student and their family members. The focus is upon the teacher to adapt to the child; for example, the NSW Inclusive Education policy states that educational staff should "change how they teach to meet the needs of students with disability" and the ACT Strengthening Inclusive Education Discussion Paper states that teachers need to be flexible in the delivery of education to ensure access for students with diverse needs.

The **community** views survey recommended that broader use (and consistent use) of accommodations, adjustments, and supports would help to reduce or remove some of the problems autistic people experience in the educational setting. A quarter of respondents also stated that education works well for autistic people when accommodations are made and the appropriate support is provided. An additional 16% of people felt that educational settings work well for autistic people when educators collaborate with the autistic student and their family, with some providing specific examples of how this works best for planning accommodations and adjustments.

Steps that can be taken to move from the current to the improved future state include:

- Introduce "teaching to diversity" as the norm within schools and set expectations that each lesson will be proactively designed to cater for diverse learning preferences and needs. Pre-service teaching qualifications could include assessments which assess teachers' ability to proactively plan lessons which cater for diverse learning preferences and needs
- Co-development of professional development resources which explain the most frequent adjustments or accommodations and why they can enable autistic young people to access the curriculum. This could be offered in pre-service teaching qualifications but also offered as ongoing training as it would likely be updated and accessed by educational staff other than teachers (e.g., university lecturers)
- Co-development of professional development/training (which includes practice-based assessments) that explains how common cognitive and/or emotional experiences of autistic people may impact a student's ability to be successful with standard pedagogy, instruction, or assessment processes. The practice-based learning aspect would help teachers or educational staff to gain experience and feedback in adapting and tailoring pedagogy, instruction, and/or assessment processes to be more accessible (and therefore inclusive) for autistic students
- Co-development of interventions or strategies that autistic students can learn and use to build self-advocacy for adjustments and supports, tailored to primary, secondary, and postsecondary settings
- Clear methods (which are explicitly taught) for autistic students to communicate to others (e.g., parents, special educational needs coordinators) when adjustments or accommodations are not provided. This would help to identify problems with accommodations not being provided early on, and could identify if there are specific times or subjects where the accommodations are not being provided
- Standardised brief, easy to understand accommodations/adjustment action plan documentation in the form of a quick "checklist" which could be read by any teacher taking any lesson. The design would ensure that it is easy for staff and students to understand. It would clearly state the accommodations/adjustments that will be provided, in which subjects/lessons, and until when the accommodation/adjustment is to be provided (review date). This would also explicitly state that the accommodations/adjustment cannot be changed until a review, and only when the student and family input has agreed to the change. The description of why, and the goal that the accommodations/adjustment is helping to achieve, would still be described in a student's learning plan.

3.3.7.4 There is need for improved inclusive education founded on acceptance of diversity that extends beyond the classroom and into school systems, processes, peer groups, and the broader community

Current state

The ACT Strengthening Inclusive Education discussion paper within the **policy** review states that placing students with disabilities within mainstream classes without accompanying structural changes to, for example, organisation, curriculum, and teaching and learning strategies, does not constitute inclusion. As noted above, the community views survey results highlighted that many autistic students are not receiving the reasonable adjustments or tailored teaching strategies to meet their needs). However, the **community views** also highlighted that autistic students also experience problems in relation to structural and systemic expectations of schools (e.g., rules, routines, expectations), with some preferring to attend special education schools rather than mainstream settings Additionally, the community views survey highlighted a problem in that autistic students have to engage in a curriculum that is based on neurotypical standards and cannot be adjusted. Bullying (including bullying by staff) was also noted as an issue for autistic people in education settings. Within postsecondary education, similar challenges with university structures and social elements of university (including bullying) were also noted.

The postsecondary research landscape mapping highlighted that while postsecondary peers may play an important role in supporting autistic students, limited research has explored evidence-based methods for building understanding of autism among these groups.

Improved future state

Now that this work has documented the impact of educational systems and processes on autistic students being able to access the curricula and education, it is important that steps are taken to address this into the future. The **policy** review highlights that the Disability Discrimination Act (1998) states that it is unlawful for an education provider to discriminate by developing curricula which has content that will exclude a person or place the person to any detriment. State-based inclusive education policies indicate that all students, including those with a disability, should be able to access, participate in, and fully engage in curricula alongside their peers (e.g., Queensland Department of Education Inclusive Education Policy 2021) and are “included in a way that suits them” (ACT Inclusive Education for Children and Young People with Disability in ACT Public Schools, 2021). The Review of the National School Reform Agreement (2022) highlighted that schools should strive to eliminate discrimination, which aligns with multiple state policies.

The **community** views survey suggested that collaboration and consultation with autistic and/or neurodivergent people, including having autistic and/or neurodivergent people working in policy and practice in education, could help to address some of the problems that autistic people face in relation to education. This could also assist in identifying way to enhance inclusive education in mainstream settings. The community views survey highlighted that educational settings work well for autistic students when systems and processes are adapted to meet the needs of autistic students, for example, allowing flexible attendance, delivery modes, off-campus learning, and amended session structures.

Steps that can be taken to move from the current to the improved future state include:

- In addition to “teaching to diversity” noted above, there should be proactive planning for diversity in terms of curricula, systems, and processes. This is relevant to primary, secondary, and postsecondary settings.
- Discussions with the community and Departments of Education regarding personalisation of attendance/engagement requirements for autistic students
- School-wide or university-wide initiatives which focus on acceptance of diversity and minimising of bullying (for a UK resource see anti-bullyingalliance.org.uk/sites/default/files/uploads/attachments/Autism and bullying guide 202023_FINAL.pdf). This would be further

- impacted by similar community-wide initiatives which aim to enhance community respect and value for diversity. Any such strategy should include a clear pathway where autistic students feel safe and supported to report bullying or discrimination, and where they are able to know action will be taken
- Provide guidance and information (based on research) to educational settings as to the benefits and challenges of different types of learning approaches that are effective for autistic students, including online learning environments for all educational settings.

3.4 Employment

3.4.1 The "1,000 Insights" community views survey

A total of 526 respondents answered at least one of the questions on employment. This included 305 autistic people and 313 family members or carers of autistic people. The 10 most frequently reported responses are detailed within this section. On occasions when there are multiple responses with the same frequency in the tenth position, the total number of responses reported will be greater than 10 to ensure all categories with equal frequencies in the tenth position are represented.

The tables for each question describe the response categories (with example participant responses) in order from the most frequently reported to the least frequently reported. For each category, percentages are provided to indicate the proportion of a respondent group whose response reflected the specific category. These groups are: (a) the entire sample (i.e., everyone), (b) autistic people, (c) family members/caregivers of autistic people, and (d) all respondents who are not represented in one of these groups.

3.4.1.1 Problems experienced by autistic people in relation to employment

A total of 526 respondents opted to answer this question on employment. This included 305 autistic people and 313 family members or carers of autistic people. The problems experienced were coded into 17 categories, which fall under the following eight broad areas:

- Lack of education and awareness about autism in the workplace, which can lead to discrimination, stigma, stereotyping, and bullying in the workplace
- Support from employers with flexible working arrangements
- Problems with fitting in the workplace due to communication and sensory barriers
- Finding a job and navigating the process related to it
- Access to support and training if required in the workplace
- Access to work environments developed considering the needs of autistic people
- The fatigue of navigating the job activities and masking
- Being able to have promotions and get leadership roles.

Table 22 ranks the 10 problems that autistic people experience in relation to the employment service (based on the survey responses). The data are ranked from most frequently reported to least frequently reported problems across all respondents. The right-hand columns report the proportion of specific respondent groups that identified this as a problem. Note that respondents often identified within multiple groups (e.g., autistic and a parent/caregiver of an autistic child), so the number of respondents in subgroups exceeds the total number of all respondents.

Of note is that these data show that approximately:

1 in 3 respondents highlight that autistic people get discriminated, stigmatised and bullied at work.

1 in 3 respondents highlight that autistic people cannot access a flexible workplace or support at their workplace.

Almost 1 in 3 respondents highlight that autistic people find navigating the social interactions and communications at work challenging.

Nearly 1 in 3 respondents highlight that autistic people feel there is a lack of understanding about autism and the needs of autistic people at workplace.

1 in 4 respondents highlight that autistic people find the process of finding a job challenging.

Table 22: 10 most frequently reported problems experienced by autistic people in relation to employment

Rank	Problems experienced by autistic people in relation to employment and sample quotes from responses	Direct insight	% who stated this as a problem			
			All respondents *N* = 524	Autistic people n = 305	Family member/ caregiver of autistic person n = 313	Other respondent groups* n = 250
1	**Experiencing discrimination, stigma, stereotyping, and bullying** (e.g., autistic people are experiencing discrimination, stigma, stereotyping and bullying and this is affecting their ability to gain and/or maintain employment)	*"Discrimination in the workplace. Employers will not accept difference as a part of the application process, and if they do, you are shoved into some sort of "autism appropriate" occupation."* (ID 935)	31%	32%	30%	33%
2	**Access to flexible work environment and supports from employers** (e.g., autistic people are having difficulty accessing supports or flexibility in the workplace that enable them to work well)	*"Workplace accommodations that are being asked for are being denied, ignored or "forgotten" about."* (ID 162) *"Lack of freedom in some workplaces to do work in way that suits (e.g., everyone having to do work in same way and in same place rather than having freedom to work in quiet space or in way that still gets job done but feels more natural to the autistic person)."* (ID 1022)	30%	32%	32%	35%
3=	**Challenges of navigating the neurotypical socialisation governing workplaces** (e.g., it can be difficult for autistic people to "fit in" at work because the way they communicate and socialise may be different)	*"Being misunderstood, and considered 'rude' in the workplace, for example from not saying hello to everyone in the morning, or being too blunt with others."* (ID 1322)	27%	29%	24%	27%
3=	**Lack of understanding about autism and the capabilities and needs of autistic people** (e.g., many employers and co-workers have very little knowledge about the strengths and needs of autistic employees)	*"Very little understanding concerning autism with employers."* (ID 452)	27%	23%	29%	27%

Rank	Problems experienced by autistic people in relation to employment and sample quotes from responses	Direct insight	% who stated this as a problem			
			All respondents *N* = 524	Autistic people n = 305	Family member/ caregiver of autistic person n = 313	Other respondent groups* n = 250
5	**Navigating how to find a job and its related processes** (e.g., attending interviews etc can be challenging when you may not communicate and behave in the same way as neurotypical people)	*"Speaking for myself, getting though an interview to get a job felt like a major challenge, why I haven't changed companies in many years. Small issues for social norm like struggling with eye contact and small talk through to talking about self and thinking on the spot, topped off with rejection sensitive dysphoria."* (ID 911)	24%	27%	27%	22%
6	**Workplaces not suitable for autistic people** (e.g., autistic people often feel uncomfortable in their workplace)	*"Environmental barriers such as open plan offices, noisy and bright environments, no options for low-sensory spaces to work in or have breaks in."* (ID 1494)	12%	13%	13%	13%
7=	**Workplace not accommodating for sensory issues** (e.g., the sensory issues of autistic people are not taken into account and accommodations are not always made by employers)	*"Working environments are not set up to accommodate individuals with sensory issues (uncomfortable chairs, loud music, open offices, fluorescent lights."* (ID 1215)	10%	13%	9%	11%
7=	**Keeping a job and meeting its requirements** (e.g., autistic people may have challenges in keeping a job and meeting the usual requirements expected of employees)	*"Maintaining employment due to demands that lead to Autistic burnout living."* (ID 1330) *"Work schedules not accommodating for periods of regulation after intense periods of high social demand."* (ID 602)	10%	12%	9%	10%
9=	**Lack of training about working with an autistic person** (e.g., most employers and work colleagues do not have any training in how to interact and work with autistic people)	*"Employers/Employees not taking the time to actively listen, learn and understand the person, how they see things."* (ID 1285)	9%	6%	8%	7%

Rank	Problems experienced by autistic people in relation to employment and sample quotes from responses	Direct insight	% who stated this as a problem			
			All respon-dents *N* = 524	Autistic people n = 305	Family member/ caregiver of autistic person n = 313	Other respondent groups* n = 250
9=	**Limited job opportunities for autistic people** (e.g., job opportunities for autistic people may be limited)	*"Hard to get employed sometimes due to many reasons such as presenting awkward/shy/weird in interviews, or feeling anxious to apply for jobs in fear of the unknown- in my case, it was easy to get employed for a job I applied for but I found that I burnt out very quickly and had to quit after 6 months"* (ID 1472)	9%	6%	10%	10%

Note. *all other groups that have not been identified separately

3.4.1.2 Factors causing the problems experienced by autistic people in relation to employment

A total of 490 respondents opted to answer this question on employment. This included 272 autistic people and 299 family members or carers of autistic people. The factors that respondents felt were causing or leading to the problems experienced by autistic people with employment were coded into 15 categories. These categories fall under the following seven broad areas:

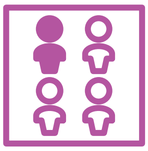
- A lack of understanding and awareness about autism, leading to bullying and discrimination
- Training and education about autism (including associated strengths and needs) is needed in the workplace to reduce discrimination and improve acceptance
- Support at work and flexible working arrangements
- Incentives for employers to hire autistic people
- Incorporate autistic perspectives at work and allocate them to roles best suited to their strengths
- Suitable workplace and accommodation
- Limited job opportunities.

Table 23 ranks the 13 most commonly reported factors that respondents felt were causing the problems that autistic people experience in relation to employment reported above. The data are ranked from most frequently reported to least frequently reported problems across all respondents. The right-hand columns report the proportion of specific respondent groups that identified this as a problem.

Importantly, these data show that:

More than half of respondents stated that the problems were due to a lack of understanding about autism and strengths and needs associated with it in the workplace.

1 in 3 respondents reported that the problems were due to a lack of training for employers about how to support their autistic employee in the workplace.



1 in 4 respondents stated that the problems were due to the culture of the workplaces not being inclusive.

Table 23: 13 most frequently reported factors causing the problems experienced by autistic people in relation to employment

Rank	Factors causing the problems experienced by autistic people in relation to employment and sample quotes from responses	Direct insight	% who stated this as a problem			
			All respon-dents *N* = 478	Autistic people n = 269	Family member/ caregiver of autistic person n = 291	Other respondent groups* n = 238
1	**Lack of understanding, awareness or acceptance of autistic people, leading to ignorance and misinformation** (e.g., there is a general lack of understanding, awareness and acceptance of autism in the community. This leads to ignorance and misinformation being perpetuated in the workplace)	*"Ignorance and stereotyping about autism. Being scared of difference, being scared of problems."* (ID 48)	58%	54%	59%	61%
2	**Lack of training and education about autism in the workplace** (e.g., very few employers, HR officers or other staff have any education or training about autism and how it might present in the workplace)	*"HR understanding of what autism is, inclusion education for all staff members."* (ID 233)	32%	21%	36%	36%
3	**Lack of support from employers** (e.g., many employers do not give adequate support or accommodations to their autistic employees)	*"Lack of accommodations in workplaces for autistic people."* (ID 151) *"Lack of ongoing support and empowerment to sustain and retain people once they commence work."* (ID 959)	31%	36%	32%	33%
4	**Workplaces' ableist culture and limited willingness to change** (e.g., a lot of employers are not willing to make changes to the ways they have always done things)	*"Inability to adapt to change, update knowledge and show compassion to autistic employees."* (ID 753)	26%	27%	23%	31%

Rank	Factors causing the problems experienced by autistic people in relation to employment and sample quotes from responses	Direct insight	% who stated this as a problem			
			All respon-dents *N* = 478	Autistic people n = 269	Family member/ caregiver of autistic person n = 291	Other respondent groups* n = 238
5	**Discrimination, stigma, stereotyping, and bullying at work** (e.g., autistic people are often a target of workplace discrimination or bullying)	*“Discrimination - which is hidden, not overt enough to fight.”* (ID 639) *“Co-workers perception of flexibility and supports as preferential treatment increasing potential for bullying.”* (ID 1020)	24%	25%	25%	23%
6	**Communication and interaction differences** (e.g., there is a lack of understanding that autistic people may communicate or interact with people differently)	*“Being reprimanded and discouraged for communicating in more comfortable ways i.e. email rather than face-to-face, or needing to ‘smile’ to be considered friendly.”* (ID 842)	21%	22%	21%	21%
7	**A workplace culture dominated by deficit-based models of autism and not acknowledging the autistic employees’ strengths** (e.g., most employers seem to know about the challenges that autistic people may bring to the workplace, but know nothing about their strengths)	*“Lack of knowledge about the special skills, talents, attributes, thinking, and communication styles people with autism have and can bring to a workplace.”* (ID 1440)	15%	18%	16%	17%
8	**Finding a job can be taxing for autistic people** (e.g., very few accommodations are offered to or made for autistic people which would make the process of getting a job easier for them)	*“The people making the recruitment decisions and then managing staff don't know anything about autism and/ or don't communicate with the autistic person to ask what they need to participate in recruitment processes or function in their role.”* (ID 159)	13%	15%	13%	9%
9	**A dominant capitalist culture** (e.g., profits are valued more highly than people)	*“Capitalism. Yeah I know, but a system that at its core values profit ahead of societal good definitely contributes.”* (ID 1075)	9%	9%	9%	11%

Rank	Factors causing the problems experienced by autistic people in relation to employment and sample quotes from responses	Direct insight	% who stated this as a problem			
			All respon-dents *N* = 478	Autistic people n = 269	Family member/ caregiver of autistic person n = 291	Other respondent groups* n = 238
10=	**Limited job opportunities for autistic people** (e.g., potential employers not willing to take a chance on employing an autistic person)	*"Attitudes that we will cost money to accommodate so it's not viable to employ us."* (ID 1410)	8%	7%	8%	8%
10=	**Workplace environment not accommodating for autistic people's needs** (e.g., the needs of autistic people are often not able to be met in the workplace environment)	*"Office layouts, particularly open-plan or shared offices, without individual offices, or quiet places to work. This environment, as well as having to mask / camouflage for extended periods of time, is exhausting to neurodiverse people, and actually prevents me from working effectively."* (ID 1458)	8%	10%	8%	8%
10=	**Limited support available to autistic people in workplace** (e.g., some employers expect the autistic employee to work out what accommodations they want, rather than working with them to accommodate their needs)	*"Placing the burden on people with disabilities to actively set out reasonable adjustments that can be made."* (ID 873)	8%	5%	9%	8%
10=	**Lack of flexible working options** (e.g., many employers do not realise that accommodating for autistic needs will increase productivity; do not allow flexible working arrangements)	*"Companies believing that flexible working arrangements will decrease productivity or needing to be open during business hours and needing employees to work then."* (ID 1051)	8%	9%	9%	8%

Note. *all other groups that have not been identified separately

3.4.1.3 Factors that could prevent or reduce the problems experienced by autistic people in relation to employment

A total of 449 respondents opted to answer this question on employment. This included 253 autistic people and 274 family members or carers of autistic people. The factors that respondents identified as preventing or reducing the problems experienced by autistic people with employment were coded into nine categories. These categories fall under the following six broad areas:

- Training and education about autism (including associated strengths and needs) in the workplace to increase acceptance and reduce discrimination
- Support and incentives for employers to hire autistic people
- Improve the process of getting a job for autistic people
- Support at work and flexible working arrangements
- Incorporating autistic perspectives at work and allocating them to roles suited to their strengths
- Suitable workplace and accommodation.

Table 24 ranks the 11 most commonly reported factors that respondents indicated could prevent or reduce the problems that autistic people experience in relation to accessing employment reported above. The data are ranked from most frequently reported to least frequently reported problems across all respondents. The right-hand columns report the proportion of specific respondent groups that identified this as a problem.

Importantly, these data show clear predominant factors highlighted by respondents:

Almost 1 in 3 respondents stated that training and educating employers and staff about autism and related strengths and challenges could prevent or reduce the problems experienced by autistic people in relation to employment.

Almost 1 in 3 respondents stated that training and educating employers and staff about autism and related strengths and challenges could prevent or reduce the problems experienced by autistic people in relation to employment.

Table 24: 11 most frequently reported factors that could prevent or reduce the problems experienced by autistic people in relation to employment

Rank	Factors that could prevent or reduce the problems experienced by autistic people in relation to employment and sample quotes from responses	Direct insight	% who stated this as a problem: All respon-dents *N* = 449	Autistic people n = 253	Family member/ caregiver of autistic person n = 274	Other respondent groups* n = 217
1	**Education and training for employers and staff at workplaces** (e.g., improving education and training about autism for all staff would improve understanding, awareness and acceptance of autistic employees)	*"Training for employers and people generally around what autism actually is. Social health campaigns around autism, neurodiversity and disability in general may also help."* (ID 882)	36%	36%	37%	33%
2	**Accommodations, mentorship, and supports from employers** (e.g., making accommodations and providing mentors and/or other required supports to autistic employees will enable them to work to the best of their ability)	*"Accommodations within the workplace to enable autistic people to work to the best of their ability."* (ID 1158)	33%	36%	32%	32%
3	**Realistic representations of autism in social media, showing what employing an autistic person means** (e.g., there needs to be more realistic depictions in the media of autistic people and what it is like to employ an autistic person. This would give potential employers a better understanding of what it might look like for them)	*"Increased promotion of what employing an autistic person looks like and avoid standardised perceptions - i.e., they are great at IT and prefer to work on their own because they don't like making friends."* (ID 690) *"Autistic people being showcased, promoted and presented as role models within their workplaces. Reframing of autistic people being different, not difficult."* (ID 852)	14%	13%	14%	17%
4	**Improved understanding of autistic strengths** (e.g., there needs to be a better understanding of the strengths that autistic people can bring to the workplace)	*"Start valuing people as people and believing that they can be contributing members of society."* (ID 1251) *"Asking people about their strengths and preferences and accommodating those where possible."* (ID 440)	13%	13%	12%	15%

Rank	Factors that could prevent or reduce the problems experienced by autistic people in relation to employment and sample quotes from responses	Direct insight	% who stated this as a problem			
			All respon-dents *N* = 449	**Autistic people** n = 253	**Family member/ caregiver of autistic person** n = 274	**Other respondent groups*** n = 217
5=	**Training and accommodations for autistic people applying for a job** (e.g., potential employers need to make adjustments to the process of employing people, so it will be more inclusive)	*"Relook at how we value workers in a society, what is required in a job interview and what is unnecessary. (e.g. If you have typed up a resume and are applying online, you don't need to input your resume into specific boxes, and then upload your resume and a cover letter that doesn't get read. That is so difficult for a neurodivergent person to complete! So many steps."* (ID 935)	11%	11%	10%	11%
5=	**Increased financial support/ incentives for employers, government funding** (e.g., the government should give financial support to employers to employ more autistic people)	*"Financial incentives for private businesses to hire and retain autistic people e.g., no payroll tax on autistic employees, along with financial penalties for discriminating against disabled employees which are strong enough to deter and easy to enforce so that they are actually effective."* (ID 195) *"To help influence societal change enforce quota systems in all government departments to employ people with autism. Allow government to act instead of just talk. Actively advertise and communicate the benefits of employing people with autism and celebrate the unique skills, talents and qualities they bring to a workplace. We're not all good just at IT stuff!"* (ID 1436)	11%	8%	11%	13%
5=	**Improve understanding, awareness and acceptance of autism in the workplace** (e.g., employers and other staff should have a better understanding and awareness of autism and be more accepting of autistic differences)	*"Acceptance of different work styles and preferences, including for sensory regulation."* (ID 187) *"Increased employer knowledge and understanding of how autism could effect an individual in the workplace and how best to support them with succeeding."* (ID 372)	11%	13%	8%	9%

Rank	Factors that could prevent or reduce the problems experienced by autistic people in relation to employment and sample quotes from responses	Direct insight	% who stated this as a problem			
			All respon-dents *N* = 449	Autistic people n = 253	Family member/ caregiver of autistic person n = 274	Other respondent groups* n = 217
5=	**Boost inclusivity culture at workplace** (e.g., there needs to be more willingness to change and improve attitudes towards including more diverse people)	*"A top-down culture change that is precipitated by open communication about differences. Changes to policies and procedures affected by the employee lifecycle. Opening up a channel for employees with neurodiversity (or disability in general) where there is forum for constant communication to senior levels of management Awareness training for all would be- or already are- managers, regardless of whether their employees have disclosed disability."* (ID 1415)	11%	11%	13%	14%
9=	**Improve discrimination, stigma, stereotyping and bullying in the workplace** (e.g., there should be a willingness to make changes to workplace procedures and policies to protect autistic people)	*"Improve stigma around autism by education (sic) the public. Supports in the workplace available to all"* (ID 1411) *"More stringent policies that businesses must comply to for Neurodiverse people Easier way to report any instances of bias and other negative issues Rewarding businesses for being neurodiverse friendly. Not superficially ND [neurodiverse] friendly."* (ID 417)	8%	5%	9%	6%
9=	**Develop job readiness programs for autistic people** (e.g., autistic people may benefit from help to prepare for work from organisations and people such as Disability Employment Services, support workers and other programs)	*"Having more readily available access to workplace training that can be geared to a variety of workplace types and sizes."* (ID 330)	8%	10%	7%	8%

Rank	Factors that could prevent or reduce the problems experienced by autistic people in relation to employment and sample quotes from responses	Direct insight	% who stated this as a problem All respon-dents *N* = 449	 Autistic people n = 253	 Family member/ caregiver of autistic person n = 274	 Other respondent groups* n = 217
9=	**Listen to the thoughts and ideas that autistic people have** (e.g., autistic people often know what they want or need, so ask them to share that information)	*"Fund autistic led organisations to help autistic workers develop self-advocacy skills."* (ID 343) *"Include input from autistic staff in designing position descriptions."* (ID 532)	8%	8%	8%	10%

Note. *all other groups that have not been identified separately

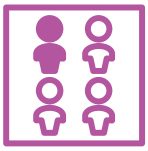
3.4.1.4 Factors that are working well, or have worked well, for autistic people in relation to employment

Overall, 381 respondents replied to this question. This included 226 autistic people and 229 family members or carers of autistic people. From these responses, the factors that, when available, are reported to be working well, or have worked well, for autistic people in relation to employment were coded into 12 categories, which fall under the following broad areas:

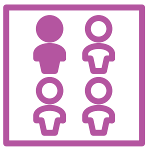
- When flexible workplace accommodations and support are available to autistic employees
- When workplaces are inclusive, and the employers and staff are aware and trained about autism
- When the job matches the autistic person's interests and strengths
- "Do not know" or nothing is/has worked well
- When there is an autism-friendly employment process available, they are self-employed, or work in small businesses
- When autistic employees are supported at work.

Table 25 ranks the 12 most commonly reported factors that respondents indicated to be working well, or have worked well, for autistic people in relation to employment. The data are ranked from most frequently reported to least frequently reported factors that are working well across all respondents. The right-hand columns report what proportion of specific respondent groups reported this as a factor that is, or has, worked well.

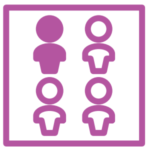
Importantly, these data show that approximately:



1 in 4 respondents expressed that when there are flexible workplaces available, employment works well for autistic people.



1 in 4 respondents stated that when the workplace culture is inclusive, employment works well for autistic people.



1 in 4 respondents stated that when the workplace accommodates their sensory needs, employment works well for autistic people.

Table 25: 12 most frequently reported factors that are working well, or have worked well, in relation to autistic people accessing employment

Rank	What is working well, or has worked well, in relation to autistic people accessing employment and sample quotes from responses	Direct insight	% who stated this as a problem			
			All respon-dents *N* = 56	Autistic people n = 34	Family member/ caregiver of autistic person n = 42	Other respondent groups* n = 56
1	**Flexible workplace arrangements** (e.g., autistic people work best when they feel supported and their workplace needs are being met; flexibility contributes significantly to that)	*"Giving reasonable accommodations to the work environment to make it more accessible."* (ID 51)	24%	32%	24%	20%
2	**Supportive employers who promote inclusivity** (e.g., inclusive employers support autistic employees to work the way that suits them best)	*"My first two bosses gave me lots of space to grow my own interests and they also allowed me extra time. They celebrated when I was right and also when I was wrong. I had two great bosses."* (ID 185)	23%	24%	22%	24%
3	**Accommodations at work supporting autistic peoples' sensory needs** (e.g., when autistic sensory needs are met, autistic people feel valued and can work well)	*"Sensory needs met whether it's regular movement breaks, lighting dimmed, work from home so noise and other sensory needs are met."* (ID 75)	22%	25%	21%	20%
4	**Colleagues who embrace inclusivity and neurodiversity** (e.g., when other staff are accepting of neurodiversity, it is easier to feel comfortable at work)	*"People who are understanding and accommodating of differences even if they do not experience those challenges themselves."* (ID 422)	17%	20%	17%	18%
5	**Employment that matches autistic people's interests or strengths** (e.g., autistic people work exceptionally well when their work tasks match their strengths)	*"If you manage to get a job and it is a role that suits your strengths you do an amazing job."* (ID 88)	12%	10%	13%	9%

Rank	What is working well, or has worked well, in relation to autistic people accessing employment and sample quotes from responses	Direct insight	% who stated this as a problem			
			All respon-dents *N* = 56	Autistic people n = 34	Family member/ caregiver of autistic person n = 42	Other respondent groups* n = 56
6	**Nothing has worked or I do not know** (e.g., for some people, nothing they have tried seems to have worked, or they do not know what is likely to work for them)	*"Nothing has worked well. ASD [autism] is taken advantage of, their technical ability, paid less for working harder, paid less than anyone else, male or female. Taken advantage of their deep and often knowledge especially their special interests."* (ID 469) *"I have no idea. I've not managed to keep one job for longer than a few years."* (ID 436)	11%	12%	11%	9%
7	**Educating employers and staff about autism** (e.g., having education sessions about autism and neurodiversity can help staff to be more accepting and understanding)	*"Workplace education campaigns focused on neurodivergent conditions (I lead this recently at my workplace with great success)."* (ID 246)	7%	5%	8%	5%
8	**Workplace routines, consistency, and clear instructions** (e.g., having regular routines and clear instructions helps autistic people to be competent and confident at work)	*"Explicit workplace feedback, with constructive information to help them know how to improve."* (ID 1079)	6%	4%	6%	8%
9=	**Supportive and autism-friendly recruitment process** (e.g., changing the recruitment process to make it more inclusive can help autistic people to gain employment)	*"A great example is Reframing Autism's options when interviewing for a job. For example, do you want to answer questions in writing, in a recording or in a telephone interview? This is a really good practice, I think"* (ID 479)	5%	4%	4%	5%

Rank	What is working well, or has worked well, in relation to autistic people accessing employment and sample quotes from responses	Direct insight	% who stated this as a problem			
			All respondents *N* = 56	Autistic people n = 34	Family member/ caregiver of autistic person n = 42	Other respondent groups* n = 56
9=	**Supported employment programs** (e.g., supported employment can be a meaningful alternative for those who may find employment on the open market to be unsuitable)	*"Supported employment is a viable option for some autistic people like my son - his provider [name of a service provider] in WA is amazing - they support his mental health challenges every day and expand his work capacity. Lots of disability advocates criticise supported employment but it does have a place for some people."* (ID 859)	5%	3%	7%	6%
9=	**Autism-specific employment or internship opportunities** (e.g., positions that are created specifically for autistic people give them opportunities to learn and show employers their skills and strengths)	*"Specialist internships for autistic people (a long work trial where they get paid, but are also learning)."* (ID 190)	5%	5%	5%	5%
9=	**Being self-employed or work in a family business** (e.g., self-employment or family businesses give autistic people opportunities to utilise their strengths in a workplace of their own, or with people who know them well, who will support them to succeed.)	*"Supporting entrepreneurship and self-employment for autistic people. I was self-employed for much of my working career so I could design my working schedule to suit."* (ID 190)	5%	7%	4%	6%

Note. *all other groups that have not been identified separately

3.4.2 Umbrella review

An umbrella review is a form of research that brings together the findings of all existing reviews (systematic and scoping) that report on a specific topic. This umbrella review aimed to identify the systematic reviews relating to any aspect of employment for autistic individuals. This included all situations related to an autistic individual being a (potential) employee, including gaining employment, maintaining employment, and employment-related skills. The terms used for the searches and the number of articles identified, screened, and included are provided in Appendix G-1 and Appendix G-2. The final umbrella review consisted of 32 articles, eight of which were written by Australian authors. More than two thirds (k = 23) of the reviews were written in the last 5 years. The 32 reviews collectively report on 865 individual studies related to employment and autistic individuals.

The information and findings from the included reviews are summarised in the subsections below. When reporting on the number of people or participants in the review, this will be represented as n = [number of participants]. When reporting on the number of reviews that considered a topic, this will be represented as k = [number of reviews].

3.4.2.1 Participants within included reviews

In total, the reviews that reported total sample sizes included 205,864 participants, with sample size for individual studies ranging from 1 to 49,623. Only six of the 32 reviews reported the overall sample size mean, standard deviation, or median of their included studies. Of the total reported participants, 201,217 (97.74%) were reported to be, or presumed to be, autistic.

Only 16 systematic reviews provided information on the gender of autistic participants. The majority of the autistic participants in these 16 reviews were male (average percentage = 78.26%). Autistic participants, or the case studies reported, ranged in age from four to 70 years.

3.4.2.2 Quality of included reviews

The quality of the included systematic reviews was assessed using the JBI Critical Appraisal Tool for Systematic Reviews. This tool assesses the methodological quality of a systematic review. The maximum score is 33, which indicates a very high-quality systematic review. The average quality score for the 32 included systematic reviews was 27.41 (83.05%), with the quality score ranging from 17 to 32.

3.4.2.3 Topics of included reviews

The 32 reviews identified in the area of employment covered six topics. These were interventions to support employment or employment-related skills (k = 20), predictors of employment for autistic people (k = 5), experiences of employment from the perspective of autistic people (k = 3), benefits of autistic employment (k = 2), barriers and facilitators to employment for autistic people (k = 1), and international policy related to employment of autistic people (k = 1). The key findings for each topic are presented in Table 26.

3.4.2.4 Research gaps

After reading the 32 reviews, the research team identified a number of key research gaps. These are combined, with relevant research gaps noted within the reviews, and summarised into Table 26. While there were several reviews of interventions and supports for autistic people to gain employment or improve employment-related skills, there are still several gaps in this research area, such as a lack of understanding about what autistic people consider meaningful employment-related outcomes, and a need for higher quality research to evaluate interventions and programs, including their effect on long-term employment outcomes.

A range of factors were identified as predictors of employment in the research literature. These included higher IQ, family supportiveness, level of education, and the presence of workplace supports. Further research is required to develop and evaluate strategies to address the negative employment predictors, such as the presence of co-occurring conditions or being part of a racial or ethnic minority.

There also appears to be a need for greater research around workplace experiences, accommodations, and the impacts of the work environment on employment outcomes for autistic people. The research identified that non-disclosure of an autism diagnosis is a large barrier to accessing accommodations. The identification of strategies to support safe-disclosure is needed. There also appears to be a need to understand the differences between autistic employees' and their employers' perspectives on workplace supportiveness, as this appears to differ between the two perspectives.

Table 26: Umbrella review findings for employment

Topic	Number of reviews on topic; citations	Key findings	Key research gaps identified
Interventions for employment or employment-related skills	*k* = 20 (Anderson et al., 2017)* (Barbaro & Sharardass, 2022) (Bross et al., 2021) (Carnett et al., 2022) (Chen & Yakubova, 2021) (Davis et al., 2019) (Fong et al., 2021) (Kim et al., 2022) (Le et al., 2021) (Lorenc et al., 2018) (Lounds Taylor et al., 2012) (Mak & Zhao, 2020)* (Munandar et al., 2020) (Ogawa et al., 2021) (Schall et al., 2020) (Seaman & Cannella-Malone, 2016) (Speyer et al., 2022)* (Walsh et al., 2017) (Weld-Blundell et al., 2021)* (Westbrook et al., 2015)	**Relating to sheltered employment:** • Evidence does not support sheltered employment as a recommended strategy to support competitive employment • Some evidence suggests that sheltered employment results in worse outcomes compared to pre-employment **Technology-based supports** • Virtual reality was used for interview training and to learn job-specific task skills • Video modelling was frequently used to improve both interviewing and job-specific task skills **Vocational training programs:** • Project SEARCH with ASD improved employment outcomes (including open employment) compared to control (high school special education services); some studies reported this program as the most evidence-based support **Social skills training programs** • Some programs reviewed included PEERS, and other non-manualised social skills training programs	• Future studies should be of a higher methodological quality • Future higher level of evidence studies are required (e.g. RCTs) • Studies should include larger sample sizes, and longer follow-up periods • Studies should be conducted in more naturalistic settings, and evaluate the generalisability of • Future evaluation of supports for employment for autistic people should be conducted with more diverse samples (including age, gender, ethnicity, presence of co-occurring conditions) • Meaningful outcomes of employment interventions should be explored and understood from the perspective of autistic people and their families • Supports should aim to target skills relevant to desired employment types • Further research is required to continue to explore the benefit of technology-based interventions, psychosocial interventions, peer supports, advocacy programs, programs to support family members, and allied health (e.g., occupational therapy) • Further research is required to continue to explore supports targeting language and communication, interviewing, increasing independence in the workplace, accessing ‘customised employment’, and developing ‘soft’ skills

Topic	Number of reviews on topic; citations	Key findings	Key research gaps identified
Predictors of employment	*k* = 5 (Eilenbeg et al., 2019) (Holwerda et al., 2012) (Pillay & Brownlow, 2017)* (Schwartzman & Corbett, 2022) (Scott et al., 2019)*	**Predictors of positive employment outcomes (in which positive employment includes having competitive employment or higher hours)** • Higher IQ • Higher language abilities • Level of education • Family supportiveness • Functional independence • Higher income/socioeconomic status (family) • Workplace supports • Autism-related strengths **Predictors of negative employment outcomes** • More 'severe' autism symptoms • Co-occurring conditions • Maladaptive behaviours • Difficulties with social skills and communication • Lack of motivation • Institutionalisation • Being part of a racial or ethnic minority	• Lack of appropriate measures for assessing employment interventions • Need to build understanding of what constitutes successful employment outcomes from the perspective of autistic people • Need to build understanding of intersectionality and impact on employment (e.g., mechanisms to understand the relationship between racial and ethnic identity and employment outcomes) • Greater need for adequate interventions and services to support autistic people in employment • Need for higher quality studies on predictors of work participation (e.g., longitudinal studies) that consider the person-environment fit

Topic	Number of reviews on topic; citations	Key findings	Key research gaps identified
Experiences of employment	*k* = 3 (DePape & Lindsay, 2016) (Hayward et al., 2018)* (Lindsay et al., 2021)	• High levels of unemployment or underemployment were identified for autistic people • Employment could be matched to a person's interests and skills, and work provides meaning to autistic employees • Rates of disability disclosure in autistic employees ranged between 25% and 69% • Reasons for non-disclosure include fear of judgement, stigma, and discrimination • Benefits of disclosure included greater acceptance in the workplace, access to accommodations, greater awareness of autism in the workplace, and possible friendship development • When disclosing their autism diagnosis, many employees did not discuss their strengths and strategies to overcome challenges • Workplace context and culture was a significant factor affecting disclosure, alongside the person's individual attributes and the level of understanding and knowledge of their co-workers • While a significant number of autistic employees were receiving workplace accommodations, a significant number were not receiving any, or they wanted to receive more autism-specific accommodations; this may be impacted by disclosure rates • Accommodations included: – Adjustments to the job application and interview process – Changes to job requirements to increase consistency and predictability – Environmental modifications – Flexibility to work from home or adjust their work environment – On-the-job training for core employment skills such as communication • The quality and benefit of accommodations may be perceived more favourably by the employer than the autistic employee • Employers also acknowledged the need for and value of training and support from external disability employment agencies for managers and staff	• Employment support programs should focus on supporting autistic employees and employers to understand social differences as this appears to be one of the most significant areas that many individuals struggle with in the work environment • Future research should identify ways to facilitate the transition from high school to post-secondary education and/or employment, with translation to policy • Further and more rigorous research is required to understand the different experiences, including disclosure and requesting accommodations at work, for sub-groups of autistic people, including exploring differences between genders, cultures, and ages • Further investigation is required to explore the experiences of autistic individuals who have been in the workforce for long periods of time • Greater understanding of the process of disability disclosure and how accommodations are requested and received, and the impact of social and workplace policies, is required • Further research is needed to explore the application of inclusive workplace environments as a workplace accommodation, to shift the focus to modifying the environment rather than requiring the autistic employee to change

Topic	Number of reviews on topic; citations	Key findings	Key research gaps identified
Benefits of employment	*k* = 2 (Bury et al., 2020)* (Jacob et al., 2015)*	• Employment of autistic people provides benefits to governments in the reduction of government-paid benefits and insurance, and an increase in tax contributions • The economic cost of providing vocational rehabilitation to autistic individuals can be considered a 'worthwhile investment' as they have a high likelihood of becoming employed after receiving appropriate supports • Employment of autistic adults significantly reduces the lifetime cost of autism in terms of lost productivity, as well as decreasing reliance on adult care or daily activity services • Employment of autistic individuals in sheltered workshops led to higher costs in vocational rehabilitation compared to those employed directly in supported employment • Autistic employees have been shown to maintain consistent hours worked for a significant period of time, and show an interest and motivation to work, making them valuable for employers who are seeking reliable employees • Autistic employees can bring strengths and values to the workplace, including: o Attention to detail o Sensory strengths (vision, taste, hearing, etc.) o Tolerance for repetitive tasks o Special interests o Adherence to rules and protocols	• Further research to identify incentives for employers is required, as overall societal cost benefit is unlikely to be sufficient • Further research is required to explore costs, benefits, and cost-benefit ratios of employing autistic individuals, particularly from the perspective of employers • Ecologically valid research is required to gain a deeper understanding of restricted and repetitive behaviours and interests, and the mechanisms that underpin the potential advantage autistic employees may bring to the workplace • More ecologically valid research is required to gain a more accurate and individualised understanding of the strengths and support needs of autistic employees

Topic	Number of reviews on topic; citations	Key findings	Key research gaps identified
Barriers and facilitators to employment	*k* = 1 (Khalifa et al., 2019)	Described impact of environmental facilitators and barriers to employment outcomes as including: **Products and technology** • Technology-based interventions and supports, such as video modelling, video-based prompting, covert audio coaching were beneficial • Low-tech interventions, such as visual prompts and schedules and communication devices, were beneficial **Support and relationships** • Supports offered by employers to employees including on-the-job training, explanation about workplace culture, and direct communication styles were beneficial • Supports offered by external job coaches/supports to employees, including for the job application process, training for specific skills (e.g., communication and interpersonal skills), were beneficial • Supports from external disability service providers for employers, including building capacity of employers and co-workers to understand and support the needs of an autistic employee, were valued **Attitudes** • The attitudes of colleagues and employers were highly influential on the success of autistic employees; supervisors of autistic staff should be respectful, patient, and understanding. **Services, systems, and policies** • Specific employment support programs were found to be beneficial, and included supports for job seeking, job site training, and long-term supports	• More research is required in the area of workplace accommodations • Need to explore the implementation of more workplace accommodation services • Need to establish a standard process for assessing abilities and accommodations for autistic people in the workplace
Policy related to employment	*k* = 1 (Bunt et al., 2020)	• Disability employment quotas were found in Germany, France, The Netherlands, the UK, Poland, Slovakia, and Romania; some countries appeared to not be enforcing these quotas, and some had replaced them with anti-discrimination laws • The same countries also had anti-discrimination laws • None of the quotas or anti-discrimination laws in any country were specific to autism	• There is a need to understand the employment rate of autistic people across different countries • Further research should focus on additional strategies to increase the employment rate of autistic people, such as employment programs and educating existing employees how to work with autistic people

* Denotes review led by Australian author.

3.4.3 Policy and guideline review

A search of publicly available domains, including government websites, search engines, and policy databases, was conducted using various combinations of the following keywords: “employment”, “workforce”, “autis/m/tic”, and “policy”. The search yielded research outputs, valuable initiatives supporting autism employment, and relevant submissions to the Select Committee on Autism inquiry. However, no government or organisational policies providing guidelines or recommendations for the employment of autistic adults were found via these search methods. Therefore, two additional search methods were utilised: (a) broadening the search terms to include “disabilit/ies”, and (b) target searching of relevant national and state government departments.

Inclusion criteria for policies or guidelines were limited to those that were current or those that had not yet been superseded. Across all states and territories, the employment of people with disabilities remains a strategic priority in disability action plans. However, no state-level policy provides specific guidance related to autism, so Table 27 summarises comments on disability more broadly. It should be noted that some documents explicitly state that they are informed by the relevant state/territory Disability Services Acts; these are not referenced in this review.

Table 27: Policy and guideline review findings for employment

Organisational level	Organisation name	Policy name	Policy date	Reference to autism	Reference to disability	Relevant information
National	Australian Government (Federal)	Australian Government Response to the Select Committee on Autism (report): Services, support and life outcomes for autistic Australians	2022	✓	✓	• For a National Autism Employment Frame to be developed to promote benefits of employment, increase employment in public and non-public sectors, and support self-employment options • Align Employ My Ability, the Disability Employment Support Model and autism-specific recommendations.
National	Australian Government (Federal)	Australia's Disability Strategy (2021-2031) Plus embedded Employ My Ability Disability Employment Strategy	2021	✕	✓	• An overall outcome for people with disability to have economic security, enabling them to plan for the future and exercise choice and control over their lives • Prioritises increased employment rates • Prioritises transition pathways from education to employment • Outlines benefits to employers and provides employer tools and abilities to confidently hire, support, develop, and retain more people with disability • Facilitates organisations to engage with their own disability action/employment plan.
State	State Government (WA)	A Western Australia for Everyone; State Disability Strategy (2020-2030)	2020	✕	✓	• Increased representation of people with disability employed in the public sector (e.g. Public Sector Commission – Workforce Diversification and Inclusion Strategy for WA Public Sector Employment 2020–2025) • Welcomes workplace cultures, opportunities for advancement, recognition as valued contributors and leaders • Equal employment requires revised recruitment processes, employment service providers, and appropriate supports to enable success.
State	State Government (SA)	Inclusive SA; State Disability Plan (2019-2023)	2019	✕	✓	• Promotes inclusive places of study that provide pathways to meaningful and inclusive employment and volunteering opportunities • Prioritises better supports within the workplace • Focus of public sector increasing opportunities under Section 65 of the Public Sector Act 2009 (SA) • Data to measure percentage of people with disability employed and retained in public sector workplaces.

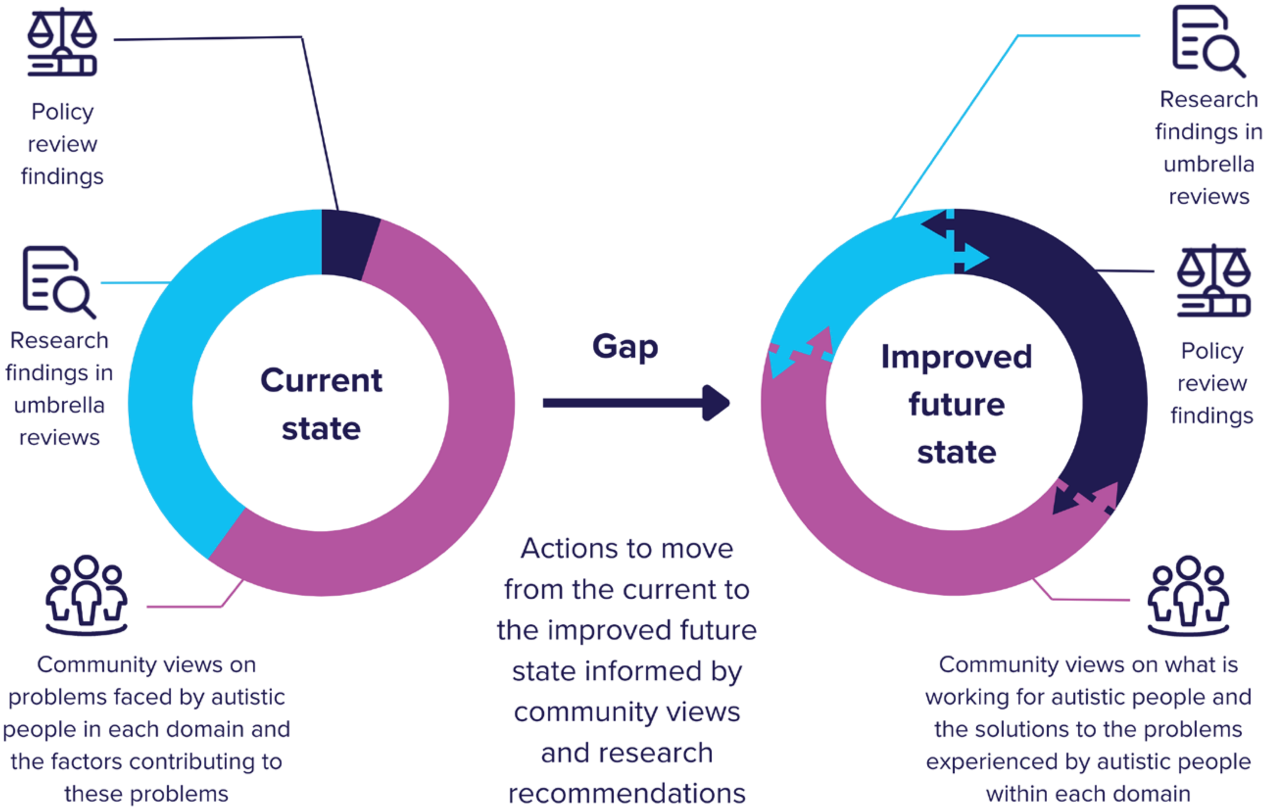
Organisational level	Organisation name	Policy name	Policy date	Reference to autism	Reference to disability	Relevant information
State	Territory Government (NT)	Northern Territory Disability Strategy (2022-2032) Northern Territory Disability Strategy Action Plan (2022-2025)	2022	×	✓	• Employment to allow participation in the economy and to be financially secure • Support for employers to be disability confident • Expand options for young people transitioning from school to employment • Implement the Disability Employment program • Support non-government agencies to develop and implement their own disability action plans • Specific reference to the NTPS EmployAbility Strategy 2018-2022.
State	State Government (VIC)	Inclusive Victoria State Disability Plan (2022-2026)	2022	✓	✓	• Prioritises employment and economic participation • Specific reference to some government-funded initiations such as Impact21 (Fostering skill development, transition to work and job coaches for Adults with Down Syndrome and Intellectual Disability) and Microenterprise (supporting small business success for people with disability as entrepreneurs) • Implement round tables with social enterprise sector representatives to identify resource and capability needs for implementing the Social Enterprise Strategy 2021–2025 and other opportunities including social procurement • Reference to Amaze's autism awareness campaign.
State	State Government (VIC)	Victorian Autism Plan (2019)	2019	✓	✓	• Opportunity is about having the means to control and improve your circumstances through access to education, employment, and positions of leadership and influence • For individuals to generate income through employment, business ownership, and entrepreneurship and participate freely as consumers • Increase employment of autistic Victorians • Specific reference to Every opportunity: Victorian economic participation plan for people with disability 2017-2020, Jobs Victoria Innovation Fund, Dandelion Program, RISE employment initiative to enhance employment opportunities and job-matching of autistic people.
State	State Government (TAS)	Accessible Island Tasmania's Disability Framework for Action (2018-2021)	2018	×	✓	• To lead by example with state government goals for employment opportunities, support for employers via the Tasmanian State Service Diversity and Inclusion Policy and Framework 2017–2020.

Organisational level	Organisation name	Policy name	Policy date	Reference to autism	Reference to disability	Relevant information
State	State Government (QLD)	All Abilities Queensland: Opportunities for All State Disability Plan (2017-2020)	2017	✕	✓	• Data to measure proportion of employment (with a public sector goal of 8%).

3.4.4 Community views, research evidence, and policy/guideline alignment and gap analysis

As well as the research gaps identified as part of the research landscape mapping, the gap analysis (see Figure 5 for process) allows comparison of the current state (predominantly based upon the community views analysis but also some findings of the umbrella review and policy review) to an improved future state (based upon community views around what is working well, policy review, and some umbrella review findings).

Figure 5: Gap analysis: Current to improved future state



The gap analysis work for the employment section highlighted the following elements that need to be addressed in order reduce the problems experienced by autistic people in relation to employment:

3.4.4.1 There is a need to improve the level of autism knowledge, acceptance, and understanding of those in workplaces (including employers and employees)

Current state

The **community** views survey highlighted a large amount of discrimination, ignorance, misinformation, and lack of understanding, awareness, or acceptance of autism, in the workplace. This included reports of bullying and extreme pressure to mask to fit in with other (neurotypical) employees. While some of the **research** landscape mapping noted a desire from employers for training and information about autism, autistic employees' negative experiences of discrimination, ignorance, and bullying in the workplace was not captured in the research found. State and federal strategies identified as part of the **policy** review describe providing supports to employers to improve their knowledge and skills to employ disabled people, but there is no mention of acceptance and attitudes, and this was not specifically in relation to autism.

Improved future state

The **community** views survey highlighted the need to provide training for employers and other staff about autism and how it might impact their autistic colleagues' experiences at work. Particularly, respondents noted training that highlighted the autistic strengths and understood autism as a difference rather than a disability. They described the value in having staff who understand and practise inclusion, and are neurodiversity friendly. As described in the strategies identified in the **policy** review, further supports and training should be delivered to workplaces to ensure this accepting environment for autistic employees.

Steps that can be taken to move from current to future state include:

- Co-produce training and materials to increase employers' and other staff's understanding and acceptance of autism, including specific training for HR professionals who may be managing situations that escalate to disciplinary action
- Increase the awareness of employers and employees (including autistic employees) of applicable anti-discrimination legislation and employer policies
- Further research to understand the experiences of autistic employees and discrimination, ignorance, and bullying in the workplace is required
- Further evaluation and implementation of materials such as the Integrated Employment Success Tool (IEST) that provide resources and training to ensure workplaces are neurodivergent friendly
- Further education and awareness about autism in the general community, which will influence attitudes and knowledge of those in workplaces.

3.4.4.2 There is a need to improve access to suitable workplaces and accommodations for autistic people

Current state

The **community** views survey highlighted that many workplaces were inaccessible and unsuitable for autistic employees for a range of reasons, including workplace culture, company structure and hierarchy, and physical environments. The **research** landscape mapping identified many potential accommodations that could support autistic employees; however, it was noted that being able to access accommodations relied on the person disclosing their diagnosis. The research identified many barriers to disclosing and therefore barriers to receiving appropriate accommodations. In the **policy** review, most of the strategies and policies identified focussed on broader disability supports and accommodations in the workplace, with limited reference to autism. As a sometimes “invisible” disability, autistic employees may face additional barriers to disclosure and accommodations than a co-worker with a physical disability.

Improved future state

The **community** views survey highlighted the need for workplaces to be more accessible and suitable for neurodivergent people, and for accommodations to be provided to autistic employees where required. Providing autistic employees with options and flexibility, such as being able to modify their work environment, work remotely, receive more direct and structured feedback, and changes to job requirements to provide greater consistency, greatly facilitated their success in the workplace. The **research** landscape mapping also identified a range of accommodations that were beneficial to autistic employees in the included studies.

Steps that can be taken to move from current to future state include:

- Provide training and resources to employers about creating a neurodivergent-accessible workplace (e.g., the IEST)
- Conduct further research to identify useful strategies and accommodations for autistic individuals in the workplace. These can then be shared with employers and autistic employees for whom they may be beneficial.

3.4.4.3 There is a need to develop appropriate and accessible employment pathways and opportunities for autistic people

Current state

The **community** views survey highlighted the lack of accessible and appropriate pathways into employment for autistic people, particularly as part of transition planning for young adults moving from education to employment. Without the opportunity to develop employment-related skills, autistic young people miss out on many employment opportunities. The community also noted that there are limited appropriate job opportunities available to autistic people, particularly considering the inaccessibility of many workplaces. The **research** landscape mapping identified that sheltered employment is not an appropriate pathway to encourage open employment for autistic people, and can even have negative impacts. Rather, having programs to develop autistic individuals’ strengths and match them with appropriate workplaces was encouraged.

Improved future state

The **community** views survey highlighted the need for effective and relevant employment support, such as disability employment services, and the need to match work tasks with the interests and strengths of the autistic individual. The opportunity for training and skill development relevant to employment was also described as beneficial. The **research** landscape mapping also supported developing skills relevant to job roles that were relevant to or of interest to autistic people, and having workplace supports was a predictor of positive employment outcomes. The **policy** review also identified several strategies that prioritised transition pathways to employment and the need for employment service providers.

Steps that can be taken to move from current to future state include:

- Embed programs to develop employment-related skills for autistic students in high school
- Develop evidence-based pathways from education to employment for autistic young people
- Integrate tools that identify and build on autistic individuals' strengths and interests (e.g., MyWay Employability) into transition planning and employment services
- Develop an evidence base of strategies and supports that lead to employment-related outcomes that are meaningful to autistic people and their families.

3.4.4.4 There is a need to increase the interest and openness of employers to employ autistic people

Current state

The **community** views survey identified that many employers were disinterested in, avoidant of, or hostile to employing autistic people. This was seen as being due to being unsure of how to work with an autistic person, a lack of understanding of the strengths of autistic people, or a view that employing autistic people would have a negative impact on business productivity. The **research** landscape mapping identified that employers often wanted to support autistic employees; however, they lacked the knowledge and skills on how to do so. The research also identified that employers may perceive the supports and accommodations they provide to their autistic employees as more beneficial than they actually are to the person. The **policy** review identified several targets for the employment of people with disabilities; however, there were no targets specific to autistic people.

Improved future state

The **community** views survey highlighted the benefit of having supportive management and employers who promoted inclusivity and a supportive work environment. It identified that having employers who understood autism and were open to supporting neurodiverse employees was of great benefit when seeking and maintaining employment. The **research** landscape mapping identified that supports for employers from disability service and advocacy organisations were a great facilitator to their knowledge and confidence to employ autistic people, and to support their autistic employees.

Steps that can be taken to move from current to future state include:

- Develop and provide education and resources to explain the benefits and strengths autistic employees can bring to a workplace
- Develop and provide education and resources to employers so they can feel comfortable and knowledgeable about supporting autistic employees
- Develop and provide resources for autistic employees and their employers to discuss their strengths and accommodation needs clearly to ensure they are effective
- Government programs and incentives to encourage the employment of autistic individuals
- Further research to identify, measure, and describe the benefits to employing autistic people for businesses and employers.

3.4.4.5 There is a need to improve accessibility of the job application pathway for autistic people

Current state

The **community** views survey highlighted the inaccessibility of the job application process, including interviews. Interviews were described as being a significant barrier, noting that even if the person is perfectly capable of performing the job, they may not be able to “think on their feet” or connect socially with the interviewer. The **research** landscape mapping identified that modifications to the job application and interview processes were a common accommodation provided to autistic employees.

Improved future state

The **community** views survey highlighted that adaptations to recruitment processes were of significant benefit in obtaining employment. The option to participate in job trials as a method for assessing a person’s suitability for a role was also suggested, as this provided a more accurate picture than a traditional interview of how an autistic person might perform at a job. The **research** landscape mapping included several studies that evaluated video modelling and virtual reality to prepare autistic people for job interviews.

Steps that can be taken to move from current to future state include:

- Conduct research to identify the needs and preferences related to employment interviews for autistic people and employers
- Conduct research to identify and assess the acceptability of suitable methods, other than interviews, of assessing candidates’ suitability for job roles
- Co-design, with autistic people and employers, resources for employers to assist with modifying recruitment processes to be more neurodivergent accessible.

3.5 Housing and independent living

3.5.1 The "1,000 Insights" community views survey

A total of 186 respondents answered at least one of the questions on housing. This included 105 autistic people and 122 family members or carers of autistic people. The 10 most frequently reported responses are detailed within this section. On occasions when there are multiple responses with the same frequency in the tenth position, the total number of responses reported will be greater than 10 to ensure all categories with equal frequencies in the tenth position are represented.

The tables for each question describe the response categories (with example participant responses) in order from the most frequently reported to the least frequently reported. For each category, percentages are provided to indicate the proportion of a respondent group whose response reflected the specific category. These groups are: (a) the entire sample (i.e., everyone), (b) autistic people, (c) family members/caregivers of autistic people, and (d) all respondents who are not represented in one of these groups.

3.5.1.1 Problems experienced by autistic people in relation to housing

A total of 186 respondents opted to answer this question on housing. This included 105 autistic people and 122 family members or carers of autistic people. The problems experienced were coded into 18 categories, which fall under the following five broad areas:

- Difficulties accessing safe and affordable options for supported independent living
- Lack of access to financial support and employment to make independent living sustainable
- Limited access to accommodation that is autism-friendly
- Problems with making adjustments to shared accommodation, accommodating different sensory profiles and communication needs
- Lack of support with the renting process and its related communications.

Table 28 ranks the 11 problems that autistic people experience in relation to the housing service (based on the survey responses). The data are ranked from most frequently reported to least frequently reported problems across all respondents. The right-hand columns report the proportion of specific respondent groups that identified this as a problem. Note that respondents often identified with multiple groups (e.g., autistic and a parent/caregiver of an autistic child), so the number of respondents in subgroups exceeds the total number of all respondents.

Of note is that these data show that approximately:

1 in 2 respondents highlight that autistic people cannot afford to live independently from their parents/carers.

1 in 5 respondents highlight a long wait time for accessing a rental property, especially those provided through public housing systems.

1 in 5 respondents highlight that autistic people need sustainable incomes to be able to live independently.

Table 28: 11 most frequently reported problems experienced by autistic people in relation to housing

Rank	Problems experienced by autistic people in relation to the housing and sample quotes from responses	Direct insight	% who stated this as a problem			
			All respondents *N* = 186	Autistic people n = 105	Family member/ caregiver of autistic person n = 122	Other respondent groups* n = 83
1	**Access to affordable living accommodations** (e.g., low availability of public/social housing; complex housing pathway; high rental costs; inadequate government assistance for housing)	*"Lack of support to get and sustain housing NDIS is not appropriately supporting or funding this."* (ID 105)	48%	48%	51%	53%
2	**Timely access to public housing as currently there is a long wait list** (e.g., shortage of social/public housing results in living with family or trying to get private rentals in a competitive rental market)	*"It takes a long time to get public housing and they are often dependent on family or rental market... [there is] huge shortage in current rentals and public housing, [and] waitlist is huge."* (ID 705)	21%	16%	25%	28%
3	**Ability to cover the costs related to housing** (e.g., unemployment or under-employment of autistic people affects ability to afford housing within budget; high costs of living)	*"Cost vs income - which may be lower due to not being able to work full time or struggling to find work. Poor work prospects leading to low incomes. Lack of access to employment opportunities reduces income and makes housing unaffordable"* (ID 48)	19%	23%	18%	20%
4	**Suitability of accommodation to autistic needs** (e.g., interpersonal challenges with shared housing; limited consideration for the best fit housing options for autistic people)	*"Relationship difficulties in share housing situations, including conflict arising from the person's particular sensory, privacy & communication needs. Sometimes it is better that they live alone with a pet, being able to access housing with a pet, rather than being told they cannot."* (ID 168) *"Lack of suitable options for those who can't live in group settings or with family - need bespoke options"* (ID 790)	18%	16%	19%	18%

Rank	Problems experienced by autistic people in relation to the housing and sample quotes from responses	Direct insight	% who stated this as a problem			
			All respondents *N* = 186	Autistic people n = 105	Family member/ caregiver of autistic person n = 122	Other respondent groups* n = 83
5	**Ability to choose from a variety of housing options** (e.g., lack of a range in living options)	*“Lack of understanding and putting those who don't want to live in a group home no other option but to do so”* (ID 409) *“Lack of consideration of what an individual might require and the different types of housing needed for different groups of people on the spectrum”* (ID 416)	17%	13%	19%	18%
6	**Support with navigating the renting process and its related communication and interactions** (e.g., rental process is complex and hard to understand; lack of support to assist autistic people with understanding rental processes including rental contracts)	*“The behaviour of real estate agents who manage rental properties. They are often the sort of people who try to take advantage, and Autistic people are often very vulnerable in that situation. The states that have clear rules about rental rights and responsibilities make this situation easier to deal with, but it's still a huge problem. Oh! The biggest, maybe! Rental contract instability! Rents seem to go up every time the contract renews, which is usually every six months, which often means you have to move out. It's horrendous. There is no certainty, so much fear and stress. I believe some people negotiate or some such, but that would involve dealing with shady real estate agents and reading their social cues (e.g., are they being serious or should I push here?) - a process that can be beyond the skills of many Autistic people. Getting a rental or home loan is extremely hard because of my lack of communication skills and my social anxiety. Getting bad references if you screw up when you can't cope with work or life. Real Estates often perceive you as mentally challenged and won't rent to you.”* (ID 479)	14%	18%	14%	12%

Rank	Problems experienced by autistic people in relation to the housing and sample quotes from responses	Direct insight	% who stated this as a problem			
			All respondents N = 186	Autistic people n = 105	Family member/ caregiver of autistic person n = 122	Other respondent groups* n = 83
7=	**Feeling safe when living independently** (e.g., lack of robust housing or housing that is physically and psychologically suitable for the needs of autistic people; areas where public/social housing is available may be dangerous)	*"Housing in dept housing estates can be very confronting, even dangerous to autistic people due to lots of social / drug and alcohol abuse fueling violence that gets targeted to the most vulnerable. Safe housing (by safe I mean safe to that person and their nervous system; sensory wise, accessibility wise, close to their connections etc.) is pretty much inaccessible to us."* (ID 300)	13%	8%	16%	16%
7=	**Receiving financial support from the NDIS** (e.g., inadequate funding from NDIS to support housing needs; lack of accountability within government agencies related to housing support for autistic people)	*"Lack of accountability from State Governments to provide especially for those with severe and profound autism buck passing between state and federal governments. NDIS should not artificially limit amount of SDA [specialist disability accommodation] that can be provided. Lack of housing for supported independent living. The NDIS needs to provide accommodation for people like me in this matter. I am currently living in the private rental market in a very small duplex and paying high rent. I am concerned about this rent increasing and the cost of living. I also am concerned about social isolation and lack of both awareness and support."* (ID 775)	13%	11%	13%	13%
9	**Suitability of the accommodation structure** (e.g., lack of housing designed with consideration for sensory sensitivities and spatial needs of autistic people; autistic people unable to make modification to rental houses to meet their needs)	*Autistic renters are unable to alter their homes to meet Autism specific needs such as sensory needs. Small lot sizes make neighbours noisier, which I struggle to cope with and there is a lack of privacy from neighbours. Noise and other sensory-related issues"* (ID 290)	12%	12%	11%	11%

Rank	Problems experienced by autistic people in relation to the housing and sample quotes from responses	Direct insight	% who stated this as a problem			
			All respondents *N* = 186	Autistic people n = 105	Family member/ caregiver of autistic person n = 122	Other respondent groups* n = 83
10=	**Lack of support with the rental process and with understanding a tenant's rights, having pets, routine inspections** (e.g., lack of support to assist autistic people in understanding their rights, responsibilities, and expectations related to rentals)	*"Landlords constantly showing up cuz they don't trust you cuz you're different, long contracts we usually don't get to read through until after the fact, having to be social to even get a place"* (ID 202)	11%	15%	9%	7%
10=	**Living independently** (e.g., lack of support to develop independent living skills among autistic people who desire to live alone or outside the family home)	*"Not having the life skills to live on their own. I have a son who would love to move out eventually but would struggle immensely house sharing with people he doesn't know. He struggles to clean, cook, maintain a yard and access emergency services"* (ID 594)	11%	6%	12%	13%

Note. *all other groups that have not been identified separately

3.5.1.2 Factors causing the problems experienced by autistic people in relation to housing

A total of 145 respondents opted to answer this question on housing. This included 80 autistic people and 95 family members or carers of autistic people. The factors that respondents felt were causing or leading to the problems experienced by autistic people with housing were coded into 18 categories, each falling under five broad area:

- Lack of affordable and suitable housing options
- Stigma and lack of understanding about the needs, preferences, abilities, and capacities of autistic people, at times leading discrimination
- Limited resources, funding and financial support from the government
- Lack of support and the required staff to navigate the housing systems and processes
- Lack of autistic input in amending the existing policies.

Table 29 ranks the 14 most commonly reported factors that respondents felt were causing the problems that autistic people experience in relation to housing reported above. The data are ranked from most frequently reported to least frequently reported problems across all respondents. The right-hand columns report the proportion of specific respondent groups that identified this as a problem.

Importantly, these data show that approximately:

1 in 3 respondents stated that the problems were due to insufficient affordable housing options.

1 in 3 respondents reported that the problems were due to a lack of understanding of autism amongst people who are involved in the housing process (e.g., housing organisations, real estate agents, renters).

1 in 4 respondents stated that the problems were due to limited suitable housing options.

1 in 5 respondents stated that the problems were due to limited housing availability that would accommodate an autistic person's needs.

Table 29: 14 most frequently reported factors causing the problems experienced by autistic people in relation to housing

Rank	Factors causing the problems experienced by autistic people in relation to housing and sample quotes from responses	Direct insight	% who stated this as a problem			
			All respon-dents *N* = 145	Autistic people n = 80	Family member/ caregiver of autistic person n = 95	Other respondent groups* n = 65
1	**Lack of affordable housing options** (e.g., lack of available public/social housing; high costs of rentals and high costs of living)	*"The private rental market is not affordable to most people on DSP [disability support pension] and people with ASD have support needs that normally exceed what is suitable for mainstream housing options."* (ID 60)	30%	29%	26%	35%
2	**Lack of understanding and awareness about autism** (e.g., lack of understanding of the needs and experiences of autistic people in the public, among health workers, housing organisations and the NDIA)	*"Social workers, employers, housing organisations and real estates do not understand how ASD symptoms can present and they do not fully understand the impact this has on an Autistic individual."* (ID 616)	29%	28%	18%	10%
3	**Lack of suitable housing options** (e.g., lack of appropriate social housing; lack of consideration and accommodation for the needs of autistic people; difficulties with interpersonal relationships)	*"No social housing. Being autistic makes living with others very difficult."* (ID 206) *"Group residential settings not giving autistic adults and young people voice and agency."* (ID 696)	26%	21%	15%	15%
4	**Limited government housing** (e.g., shortage of social/public housing; lack of focus on housing as a priority)	*"Lack of public housing for people at high risk."* (ID 24) *"Lack of supply of building materials, lack of insight by the government to increase housing. Limited options to support people impacted by these decisions by the government, NGO's."* (ID 705)	23%	21%	18%	12%

Rank	Factors causing the problems experienced by autistic people in relation to housing and sample quotes from responses	Direct insight	% who stated this as a problem			
			All respondents *N* = 145	Autistic people n = 80	Family member/ caregiver of autistic person n = 95	Other respondent groups* n = 65
5	**Limited resources and funding** (e.g., lack of funding for disability housing; lack of appropriate and targeted government funding for autistic people)	*"Lack of funding for disability homes."* (ID 290)	20%	14%	16%	10%
6	**Support from government (incl NDIS and DSP, rent assistance)** (e.g., inadequate funding support for housing needs; limited planning for social housing; DSP [Disability Support Pension] and JobSeeker payment inadequate support for autistic people)	*"Lack of Government support or housing options for autistic people which results in them heavily relying on family. Lack of money to look for housing independently."* (ID 47)	19%	19%	10%	8%
7	**Employment, income and work capacity issues** (e.g., limited working capacity and income potential for autistic people; high unemployment or under-employment of autistic people)	*"Many autistic people have significant permanently limited work capacity but would not qualify for the Disability Support Pension due to unfair criteria. Money - holding down a job while being autistic can be hard."* (ID 81)	15%	21%	9%	6%
8	**Support with systems and processes** (e.g., poorly integrated government systems; long processes to access support and lack of support to navigate government systems)	*"The SDA [Specialist Disability Accommodation] process is too long and difficult to manage. It took three years for us to go through with our young person, and $11,000 in assessments. Inability to Advocate for themselves and/or their families or unable to get access to an advocate support service. I can no longer access the NDIS because the amount of work involved to gain access to the support I need has become too overwhelming for me to comprehend."* (ID 91)	10%	10%	7%	6%

Rank	Factors causing the problems experienced by autistic people in relation to housing and sample quotes from responses	Direct insight	% who stated this as a problem			
			All respondents *N* = 145	Autistic people n = 80	Family member/ caregiver of autistic person n = 95	Other respondent groups* n = 65
9	**Stigma and discrimination** (e.g., lack of awareness among stakeholders about the discrimination autistic people experience; limited support available unless perceived as ‘high needs;’ real estate agents will not rent to autistic people if they perceive them as ‘mentally challenged’)	*“Shame and stigma for the person experiencing difficulties. People automatically assuming the worst about people who are different.”* (ID 381)	9%	9%	7%	3%
10=	**Renting and its related communications are complex** (e.g., lack of understanding among autistic people about the rental process, rules and social and non-verbal cues that guide negotiations when renting)	*“The rental system. It's horrendous. Horrible for everyone, but particularly for the more vulnerable, such as Autistic people... Rents seem to go up every time the contract renews, which is usually every six months, which often means you have to move out. It's horrendous. There is no certainty, so much fear and stress. I believe some people negotiate or some such, but that would involve dealing with shady real estate agents and reading their social cues (e.g., are they being serious or should I push here?) - a process that can be beyond the skills of many Autistic people.”* (ID 479).	7%	11%	5%	3%
10=	**Lack of support with activities related to housing** (e.g., lack of support to help autistic people with housing processes such as applying for rental or getting home loans; poor understanding among autistic people of how to run a household)	*“No supports available unless perceived to be ‘high needs’. Disability was mostly associated with physical access to housing. Autistic needs relate closer to normal housing but with some executive functioning assistance - hence ILO [NDIS Individual Living Options funding]. The environment and each autistic personality may be triggers to other autistic people”* (ID 381)	7%	10%	5%	3%

Rank	Factors causing the problems experienced by autistic people in relation to housing and sample quotes from responses	Direct insight	% who stated this as a problem			
			All respon-dents *N* = 145	**Autistic people** n = 80	**Family member/ caregiver of autistic person** n = 95	**Other respondent groups*** n = 65
10=	**Unknowledgeable support staff** (e.g., support staff lack sufficient education; understanding of autism and ill-equipped to help advocate for autistic people)	*"Inability to Advocate for themselves and/or their families or unable to get access to an advocate support service."* (ID 1351) *"Ignorant staff and not qualified."* (ID 597)	7%	4%	3%	2%
10=	**Government policies are a barrier** (e.g., lack of government investment or interventions to improve access to public/social housing; lack of policies that support autistic people with housing access)	*"Both commonwealth and state gov not investing sufficiently in programs that could lead to more effective housing solutions."* (ID 1227)	7%	4%	5%	3%
10=	**There is limited understanding about the abilities and capacity of autistic people** (e.g., lack of understanding among decision-makers about the needs and capacity of autistic people to guide funding allocations and policy)	*"People who make decisions have very little knowledge of the real impact a severe ASD diagnosis has on a person and family and they restrict access to services and funding that is desperately required to keep the person with ASD safe."* (ID 835)	7%	3%	6%	3%

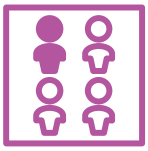
3.5.1.3 Factors that could prevent or reduce the problems experienced by autistic people in relation to housing

A total of 142 respondents opted to answer this question on housing. This included 81 autistic people and 99 family members or carers of autistic people. The factors that respondents identified as preventing or reducing the problems experienced by autistic people with housing were coded into 18 categories. These categories fall under the following six broad areas:

- More autism-friendly housing options with physical features that accommodates varied sensory profiles
- Educating the community about the needs, preferences, abilities, and strengths of autistic people
- Improved financial support or availability of affordable government housing
- Providing support, adjustment and diversity for accommodation suitable for autistic people who pursue independent living
- Improved rental systems and communications associated with it
- Improve government housing policies by increasing clarity of the processes and reducing their complexity.

Table 30 ranks the ten most commonly reported factors that respondents reported could prevent or reduce the problems that autistic people experience in relation to accessing housing reported above. The data are ranked from most frequently reported to least frequently reported problems across all respondents. The right-hand columns report the proportion of specific respondent groups that identified this as a problem.

Importantly, these data show that approximately:



1 in 4 respondents stated that providing accommodation that is more autism-friendly could prevent or reduce the problems experienced by autistic people in relation to housing.

1 in every 5 respondents identified acceptance and awareness about autism as a factor that could prevent or reduce the problems experienced by autistic people in relation to housing

Table 30: 10 most frequently reported factors that could prevent or reduce the problems experienced by autistic people in relation to housing

Rank	Factors that could prevent or reduce the problems experienced by autistic people in relation to housing and sample quotes from responses	Direct insight	% who stated this as a problem			
			All respon-dents *N* = 128	Autistic people n = 60	Family member/ caregiver of autistic person n = 88	Other respondent groups* n = 77
1	**More housing options for autistic people (incl. location, rent/own/build, structure, singles/ families, supported accommodation)** (e.g., provide more public/social housing; more supported accommodations specific to the needs of autistic people)	*"Having more housing, options for people mid-level support needs under NDIS. Actually asking autistic people what will work for them and building services based on needs."* (ID 105)	25%	21%	17%	25%
2	**Education to increase acceptance and understanding about autism** (e.g., provide autism training for housing staff, architects, families, people in the education system about the sensory and spatial needs of autistic people)	*"It starts with reforming the school system. With reforming and reframing societies perception of Autistic people. Make schools & employers more autism-friendly."* (ID 1131)	22%	20%	22%	21%
3	**More flexible financial support opportunities** (e.g., NDIS provide flexibility in guidelines and funding for home modifications; flexibility in funding different housing options)	*"Funding support to cover costs of making accommodation accessible in different ways to encourage a patchwork of accessibility. Better access to NDIS support for independent living."* (ID 77)	19%	19%	19%	21%

Rank	Factors that could prevent or reduce the problems experienced by autistic people in relation to housing and sample quotes from responses	Direct insight	% who stated this as a problem			
			All respondents *N* = 128	Autistic people n = 60	Family member/ caregiver of autistic person n = 88	Other respondent groups* n = 77
4	**Access to autism-specific support** (e.g., make schools and employers more autism-friendly; increase housing support; mandate housing as a human right)	*“More autistic training for Housing staff, along with more specialised supports, options and assistance available for autistic clients. Housing linking and partnering with more autistic based specialised supports. Supports to assist with securing and sustaining private housing. Financial 'translators' that autistic people can access for large life changing commitments and decisions. Contracts/rental agreements to be in plain language and having a support person to explain.”* (ID 446)	18%	19%	14%	16%
5	**More affordable and appropriate public housing** (e.g., increase social housing; stricter regulations on pricing for community housing providers; more rules and regulations regarding the maintenance of rental properties)	*“Need a lot more investment in affordable housing. Cheaper and safer housing options for people at the edges of society.”* (ID 935)	17%	15%	19%	16%
6	**More housing options for autistic people (incl. for singles/ families/ shared, supported accommodation)** (e.g. increase funding for single occupancy arrangements; improve selection processes for shared housing to reduce interpersonal conflicts; provide more need/preference-based housing options)	*“More individual supports and services for those who wish to live alone. More individual flats or villas for individual accommodation. More options of smaller one bedroom houses. Develop concepts of ILO [NDIS Indvidualised Living Options] much more with perhaps some innovative arrangements”* (ID 553)	14%	14%	15%	16%

Rank	Factors that could prevent or reduce the problems experienced by autistic people in relation to housing and sample quotes from responses	Direct insight	% who stated this as a problem			
			All respondents *N* = 128	Autistic people n = 60	Family member/ caregiver of autistic person n = 88	Other respondent groups* n = 77
7	**More accessible financial assistance** (e.g., better pensions to account for cost of living and housing expenses; provide rent assistance; flexibility in requirements for Disability Support Pension)	*“Loosen the restrictive requirements for the disability support pension so autistic people can access appropriate financial assistance. Many people do not get funding or the Disability Support Pension, even though they have autism because they are considered ‘too high functioning’, despite the fact that they may have extreme difficulty getting and keeping a job. Make DSP more accessible for autistic people”* (ID 81)	13%	9%	7%	12%
8=	**More autism-specific and autism-friendly accommodation** (e.g., recognise unsuitable housing; increase autism specific housing; provide specialised trained staff for supported living)	*“Create housing and supported living opportunities for neurodivergent people who do not require carers but do require consultative mentorship. We need Autism specific disability homes staffed by specially trained staff. Accommodation specifically for adults on the autism spectrum with privacy issues and other areas being addressed.”* (ID 247)	11%	14%	9%	9%
8=	**Improved and manageable renting system** (e.g., improve government policies and regulations that cap the prices of rentals; regulations that allow autistic people to make some modifications to rental properties)	*“The rental market needs regulations which allow Autistic renters to make subsidised changes to their homes (e.g., in types of heating/cooling and paint colours). The government needs to put renters first. Capping rent so it can't go up every six months, making it harder for landlords to send their minions (i.e. the real estate agents) out to harass their tenants.”* (ID 290)	11%	9%	12%	9%
8=	**Improved access to public housing, reducing wait times** (e.g., increase funding of social housing; provide more homelessness support; have special listings for autistic people)	*“Reduce the waiting lists for public housing. A special listing for people with autism.”* (ID 528)	11%	12%	10%	12%

3.5.1.4 Factors that are working well, or have worked well, for autistic people in relation to housing

Only 76 respondents replied to this question. This included 43 autistic people and 54 family members or carers of autistic people. From these responses, the factors that are reported to be working well, or have worked well, for autistic people in relation to housing were coded into 11 categories and fall under the following broad areas:

- No good options, don’t know, and needs work
- When there is access to financial/governmental support (e.g., NDIS) based on individual needs
- When autistic people live with their family/carers or other neurodivergent people
- When there are support networks that can help autistic people navigate the housing process and independent living activities
- When there is autism-specific housing available.

Table 31 ranks the 11 most commonly reported factors that respondents reported to be working well, or have worked well, for autistic people in relation to housing. The data are ranked from most frequently reported to least frequently reported factors that are working well across all respondents. The right-hand columns report what proportion of specific respondent groups reported this as a factor that is working well or has worked well.

Importantly, these data show that:

1 in 3 respondents did not feel that anything is working well for autistic people in relation to housing.

Almost 1 in 5 respondents stated that when there is NDIS support, housing works well for autistic people

Table 31: 11 most frequently reported factors that are working well, or have worked well, for autistic people in relation to housing

Rank	What is working well, or has worked well, in relation to autistic people accessing housing and sample quotes from responses	Direct insight	% who stated this as a problem			
			All respon-dents *N* = 56	Autistic people n = 34	Family member/ caregiver of autistic person n = 42	Other respondent groups* n = 56
1	**Nothing is working well/has worked well** (e.g., unable to identify any aspect of housing that is working well; feeling unsupported when trying to meet housing needs)	*"Nothing atm as we won't let our foster son move into the areas that are offered for his own safety. It's all on me. No (suitable) help (yet). Nothing much. Families have to constantly fight for services to be done competently and are always raising concerns of neglect from staff not following care plans."* (ID 504)	33%	30%	31%	33%
2	**When there is NDIS support** (e.g., NDIS support for those who qualify for supported independent living; NDIS housing support services)	*"NDIS providing supports for daily living activities."* (ID 1499)	22%	21%	15%	15%
3=	**When autistic people live with their family/carer** (e.g., living with family; having family that make accommodations for sensory and spatial needs)	*"Most autistic adults I know have struggled with housing and still live with their parents. Living with families or siblings. The ability to stay at home with family for longer has benefited some with ASD."* (ID 1091)	11%	2%	13%	13%
3=	**When autistic people are supported with independent living** (e.g., able to live alone with support; low density social housing options that allows for more independence)	*"Supported independent living is great. Having support to help look after house."* (ID 195)	11%	12%	9%	13%

Rank	What is working well, or has worked well, in relation to autistic people accessing housing and sample quotes from responses	Direct insight	% who stated this as a problem			
			All respon-dents *N* = 56	Autistic people n = 34	Family member/ caregiver of autistic person n = 42	Other respondent groups* n = 56
3=	**When there are existing support networks (including family)** (e.g., having supportive family that can assist financially or with navigating housing processes; having compatible housemates who support each other)	*"People such as parents joining together to purchase properties for their children. With strong support from my husband who has ADHD but not autistic, we were able to buy our first home together - his mother also supported us to make our first deposit to crack into the housing market. Without that, we wouldn't be home owners now."* (ID 1251)	11%	7%	33%	0%
6	**When the system is based on individual needs** (e.g., funding that is provided based on specific needs; self-advocacy important to access tailored housing support; housing that is suitable based on individual needs and preferences)	*"Flexible funding for flexible needs. We moved to a farm to support our daughter so that we could afford a big enough house that she could have her own bathroom and decent sized room to retreat. The housing solution has made a big difference but it has imposed a long commute to town for our family."* (ID 1199)	9%	7%	4%	5%
7=	**When autistic people live with other neurodivergent people** (e.g., better compatibility when living with other neurodivergent people; mutual understanding and more respect)	*"Living with other neurodivergent people. Housing with others whom they are compatible with not just all disability (not segregating)."* (ID 1227)	8%	9%	6%	10%
7=	**When there is financial support for housing and independent living** (e.g., availability of financial assistance such as rent assistance but increased funding for housing is needed)	*"RENT ASSISTANCE IS GOOD BUT NOT ENOUGH."* (ID 1199)	8%	9%	7%	3%

Rank	What is working well, or has worked well, in relation to autistic people accessing housing and sample quotes from responses	Direct insight	% who stated this as a problem			
			All respon-dents *N* = 56	Autistic people n = 34	Family member/ caregiver of autistic person n = 42	Other respondent groups* n = 56
9=	**When there is a choice for varied types of accommodation that are safe** (e.g., having a choice in housing option; housing options that are safe from violence and interpersonal conflict)	*"I like being independent and living on my own without random people showing up unannounced so being in my own peace is definitely a plus. Low density social housing options that allow for independence, tenancy sustainment and quality of life."* (ID 226)	7%	7%	4%	3%
9=	**When there are supports available for shared accommodation** (e.g., low density social housing; adapted housing with access to support as needed)	*"Disability housing with Supports in place."* (ID 1227)	7%	2%	7%	8%
9=	**When there are autism-friendly accommodations available** (e.g., living with people with similar interest and lifestyles; accommodation that is simple and easy to navigate)	*"Special housing/complex for disabled people. From lived experience with a family member I know that the Autistic person is happier, they feel safe, they have something of their own, and something to be proud of. They have their own privacy, and space. Their mental health stabilises. They feel like everyone else."* (ID 1217)	7%	2%	7%	5%

Note. *all other groups that have not been identified separately

3.5.2 Umbrella review: Housing design

Two umbrella reviews were conducted under the Housing and independent living sections namely 1) housing design and 2) independent living. An umbrella review is a form of research that brings together the findings of all existing reviews (systematic and scoping) that report on a specific topic. The first review on housing design is presented below. However, the independent living review is presented towards the end of the section as this review was conducted in response to the findings of the housing research about autistic people's independent living needs. This review focuses on the area of housing and housing design, particularly as it relates to the built environment. The search terms used, and the number of articles identified, screened, and included, are provided. Four systematic reviews were included in this umbrella review. Two of the four were led by Australian authors, and all reviews were conducted in the last 2 years. There were 96 individual studies reported across the four systematic reviews.

The information and findings from the included reviews are summarised in the subsections below. When reporting on the number of people or participants in the review, this will be represented as n = [number of participants]. When reporting on the number of reviews that considered a topic, this will be represented as k = [number of reviews].

3.5.2.1 Setting of included reviews

The articles included in the systematic reviews ranged from peer-reviewed journal articles to conference papers, reports, and grey literature. Residential settings, including family homes and group or support care homes ($k = 47$), were considered in the systematic reviews, as were a range of additional settings. These included school or learning environments ($k = 36$), workplaces ($k = 1$), plazas ($k = 1$), vocational settings ($k = 1$), laboratory ($k = 1$), outdoor environment ($k = 3$), multiple settings ($k = 4$), and general spatial design for autistic people ($k = 2$). Only one study reported on the number of participants (Dargue et al., 2021; 73 participants), while two reviews highlighted that stakeholder consultations were conducted to validate their findings (Black et al., 2021, 6 participants; Nguyen et al., 2022, 13 participants).

3.5.2.2 Quality of included reviews

The quality of the included systematic reviews was assessed using the JBI Critical Appraisal Tool for Systematic Reviews. This tool assesses the methodological quality of a systematic review. The maximum score is 33, which indicates a very high-quality systematic review. The average quality score for the four included systematic reviews was 28 (84.8%), with the quality score ranging from 27 to 29.

3.5.2.3 Topics of included reviews

The findings of the four systematic reviews identified in the area of autism and housing design can be summarised into three key topics: building structure considerations for autistic people ($k = 2$), sensory considerations in the built environment for autistic people ($k = 4$), and considerations for building interior features to accommodate autistic people ($k = 3$). The key findings for each topic are presented in Table 32.

3.5.2.4 Research gaps

Several research gaps were identified in the four reviews, which were combined with research gaps identified by the authors of this review in consultation (personal communication) with A/Prof Ebba Högström from the School of Planning at Blekinge Institute of Technology, Sweden. A/Prof Högström has conducted work in the area of planning sustainable living environments for people with psychiatric disabilities. These research gaps are summarised in Table 32.

Overall, there is a scarcity of research examining the experiences and needs of autistic people as it relates to housing design and the built environment generally. Consequently, there is a need for more high-quality research with larger samples in order to improve the generalisability of findings and translation to policy. Additionally, there is a need for research that is co-created or inclusive of autistic people as first-person sources, to ensure that their views, experiences, and needs are appropriately represented. Furthermore, there is a large gap in research related to the built environment needs of autistic adults. Much more research focuses on children, including the built classroom environment, which can be informative in understanding aspects of the environment that are supportive of autistic people.

Table 32: Umbrella review findings for housing design

Topic	Number of reviews on topic; citations	Key findings	Key research gaps identified
Building structure considerations	*k* = 2 (Black et al, 2022)* (Tola et al., 2021)	Flexible and adaptable design principles acknowledge that decisions made in the design of built environments can potentially facilitate the participation of autistic people. Some key considerations around structural elements include: • Building materials: Building materials that are easily cleaned and may provide a calming effect, such as cork, cotton, porcelain, and other natural materials are preferred. Materials that may be toxic, emit chemicals or gases, or hold dust should be avoided as they can cause unnecessary sensory stimulation. Additionally, non-slip vinyl floor coverings, durable wall paint, brick with impact resistance, and fortified windows were recommended to foster safety and reduce potential building damage that may be caused by behaviours of concern • Ceilings: Different ceiling heights should be adapted in different types of spaces based on their function. Generally, the study reported that lower ceilings improve the feeling of calm and comfort; however, higher ceilings are recommended for active, high-energy spaces. A ceiling height of nine feet (2.74m) was recommended by one study to reduce damage to building as well as reduce the risk of harm to individuals with higher support needs • Walls: Within interior spaces, half walls and curved walls help to create visual boundaries. Too many wall openings should be avoided in classroom settings as views outside may be distracting. Also, using bevelled wall corners instead of sharp corners helps to protect against injury • Entrance: It is recommended that buildings have multiple entrances and exits to help decrease noise levels and socio-sensory barriers to activity and participation for autistic people • Windows: Use double-paned or triple-glazed windows and place them above eye-level, or lower half-window covers to reduce distractions, especially in classroom settings	• Limited research available that examines the housing design and the built environment experience and needs of autistic people • Need for more high-quality studies that are rigorously conducted and generalisable to groups of autistic people • Lack of co-produced research that focuses on exploring the needs, perspectives, and experiences of autistic people related to general built environment design • Need for more experimental practices and policies about design for autism and monitoring the outcomes of these for sustainability

Topic	Number of reviews on topic; citations	Key findings	Key research gaps identified
Sensory considerations	*k* = 4 (Black et al., 2022)* (Nguyen et al., 2022) (Dargue et al., 2021)* (Tola et al., 2021)	Most autistic people have concerns related to sensory stimuli. While personal variation exists, general recommendations were made: **Orientation:** • (Workplace settings) Autistic people who are hypersensitive to sensory stimuli are recommended to sit in an area where they can see the external landscape, or on the upper levels of a building. Hyposensitive individuals are recommended to sit near echoic city views or on the lower levels of the building **Lighting:** • Natural light is preferred to artificial light • LED light is preferred to fluorescent lighting, which tends to flicker and hum • Use dimmable or adjustable lighting with diffused light source as this reduces glare • Provide shade structures and trees in outdoor spaces **Sound:** • One review suggested that average sound level should be kept at 50 dB or below • Sounds from external sources, such as rain, adjacent rooms, appliances, or passing traffic, should be reduced where possible • Spatial sequencing and zoning can be used to reduce noise transfer across spaces • Use sound-proof walls, or thick concrete walls with hard plaster finish to reduce noise transmission • Sound-absorbing floors, carpets, non-reflective sound-absorbing materials on walls and ceilings, window coverings, and under-floor heating are also useful ways to reduce noise • Sound dampening techniques such as acoustic tiles with a high noise reduction coefficient (NRC) can also be used in high noise-producing areas • Odours: strong odours can also be a major concern for autistic individuals. • Spatial sequencing can be used to group odours (e.g., grouping kitchens and pools)	• Need for more high-quality single case design studies exploring whether lighting and auditory modifications have a positive impact for autistic individuals in the home environment • Research needs to include details of the sensory profile of participants as a key descriptor in explaining research findings, so that context can be given when applying findings to real world situations and translation to practice and policy • Larger samples are needed in a variety of built environment settings to determine the impact of making sensory modifications and to enhance the generalisability of findings • Research focus on the sensory and other needs of autistic adults in the built environment, specifically related to housing

Topic	Number of reviews on topic; citations	Key findings	Key research gaps identified
Considerations for building interior features	*k* = 3 (Black et al., 2022)* (Nguyen et al., 2022) (Tola et al., 2021)	One review pointed to the importance of including autistic people in co-design of residential spaces to ensure that the space addresses their needs, helping to reduce anxiety about moving into a new space However, general recommendations focused on the importance of buildings' interior features being predictable, clear, and consistent with the order of daily routines to reduce anxiety and disorientation. These recommendations included: **Layout:** • Organise spaces in a sequential manner consistent with users' daily routine. One-way or straightforward circulations aided with wayfinding • Compartmentalise spaces into zones with clear boundaries and use wide corridors that are not too long. Circulations with sudden corners, blind corners, and abrupt transitions should be avoided • Spaces designed for socialising should be large enough to allow for personal space to be maintained without feeling crowded • Classroom settings can offer a choice of spaces to allow autistic children to navigate the classroom while allowing the teacher to see them easily • In residential care settings, floor plans should be repetitive and identical across units **Wayfinding:** • Use signs, maps, and colour coding to help navigate paths independently. Add visual features such as vegetation, distinct flooring, or walls to help with space differentiation **Quiet room:** • Provide a defined space that is low-stimulation or stimulation free to allow for calming as needed **Transition spaces:** • Transition spaces allow autistic people to orient themselves to sensory stimuli or manage social interactions (e.g., semi-private transitional spaces such as specially designed gardens, benches, and hammocks) **Clutter:** • Visual and physical clutter has been linked to disruptive behaviour among autistic children in the classroom. Keeping learning spaces organised and clean is recommended	• Research findings tend to offer generic guidelines; research is needed that defines spatial criteria in such a way that they can be truly inclusive • Need for inclusion of autistic people and their supporters in co-design and consultation related to design of residential and urban building spaces where they will be users • Increase the quantity and quality of research related to the housing design and residential situation for autistic adults • More research is needed into the meaning of home and aspects of independent living needs and experiences of autistic people in different residential settings such as group, family or living alone

Topic	Number of reviews on topic; citations	Key findings	Key research gaps identified
		Colour: • Use soft, natural colours on walls, ceilings, and floors, and avoid bright, shiny, or reflective colours. Limit colour contrasts but use distinct colours for colour coding of spaces to aid wayfinding **Patterns and textures:** • Autistic people may have difficulty processing complex and bold geometry shapes, so simple designs are recommended. A balance of smooth and rough textures, and matte-finished tiles or textures, are preferred to shiny or polished textures **Furniture and seating:** • Personal taste in living space is important for autistic adults, so they should have choice in stating their preferences. As it relates to children in the classroom, one review found inconclusive results about whether balls and cushion seating were better than other traditional forms **Indoor air quality:** • Proper ventilation and airflow is important for autistic people as many tend to be sensitive to odours. A ventilation standard of around 40 cubic feet per minute per occupant and carbon filters for the removal of particulate matter was recommended in one review	

* Denotes review led by Australian author.

3.5.3 Policy and guideline review

A search of publicly available domains, including government websites, search engines, and policy databases, was conducted using various combinations of the following keywords: “housing”, “accommodation”, “living arrangements”, “built environment”, “autis/m/tic”, and “policy”. Inclusion criteria for policies or guidelines were limited to those that were current or had not yet been superseded. This review focused on government (state, territory, and federal) policies concerning accommodations for living despite the policies including some broader discussion on built environment such as public transport, access to services and community spaces, use of technology, and access to information.

The National Disability Insurance Scheme Act 2013 legislates a participant’s plan to include living arrangements with reasonable and necessary support to enable inclusion in community as fully participating citizens. Many policies reference the NDIA as a funding source for adaptations or as an important collaborator when considering personalised housing options. Policies also reference compliance with the Liveable Housing Design Guidelines 2017, National Construction Code 2022, Australian Building Codes Liveable Housing Design Standard 2022, and Disability (Access to Premises - Buildings) Standards 2010. All are set to enable better choice for housing, to allow for adaptability, and to mandate design for physical accessibility. Notably, none of these guiding documents, nor the implemented state/territory disability plans, provide specific policy or recommendations on housing for autistic individuals. Statements related to broader disability are reviewed in Table 33.

Table 33: Policy and guideline review findings for autism and housing

Organisation name	Policy name	Reference to autism	Reference to disability	Relevant information
Australian Government (Federal)	Australian Government Response to the Select Committee on Autism (report): Services, support and life outcomes for autistic Australians (20202	✓	✓	• NDIS funded supports to consider high proportion of autistic adults living in their family home and therefore the informal burden of care on parents and independent living options following the death of the participant's parents or carers (Recommendation 68) • Review the Specialist Disability Accommodation Design Standard to ensure it accounts for the sensory issues experienced by autistic participants (Recommendation 69) which led to the NDIS Specialist Disability Accommodation Design Standard 2019 • Improved livability incorporates physical access and enhanced provision for people with sensory, intellectual, or cognitive impairment.
Australian Government (Federal)	Australia's Disability Strategy (2021-2031)	×	✓	• An overall outcome for people with disability to live in inclusive, accessible, and well-designed homes and communities • Prioritises an increased availability of affordable housing • Prioritises choice and control about where to live, with whom they live, and who comes into their home.
State Government (WA)	A Western Australia for Everyone; State Disability Strategy (2020-2030)	×	✓	• Housing to support living well • Prioritises individual choice • Plans to equip the key services workforce with the right skills and attitudes.
State Government (WA)	WA Housing Strategy (2020-2030)	×	✓	• Providing tailored housing options • Strategic focus on purpose-built, safe, financially sustainable, and well-located homes with access to services • Utilising NDIS funding opportunities for building Specialist Disability Accommodation and property modifications • Reducing pressure on social housing and decreasing the number of young people with disabilities in aged care accommodation.

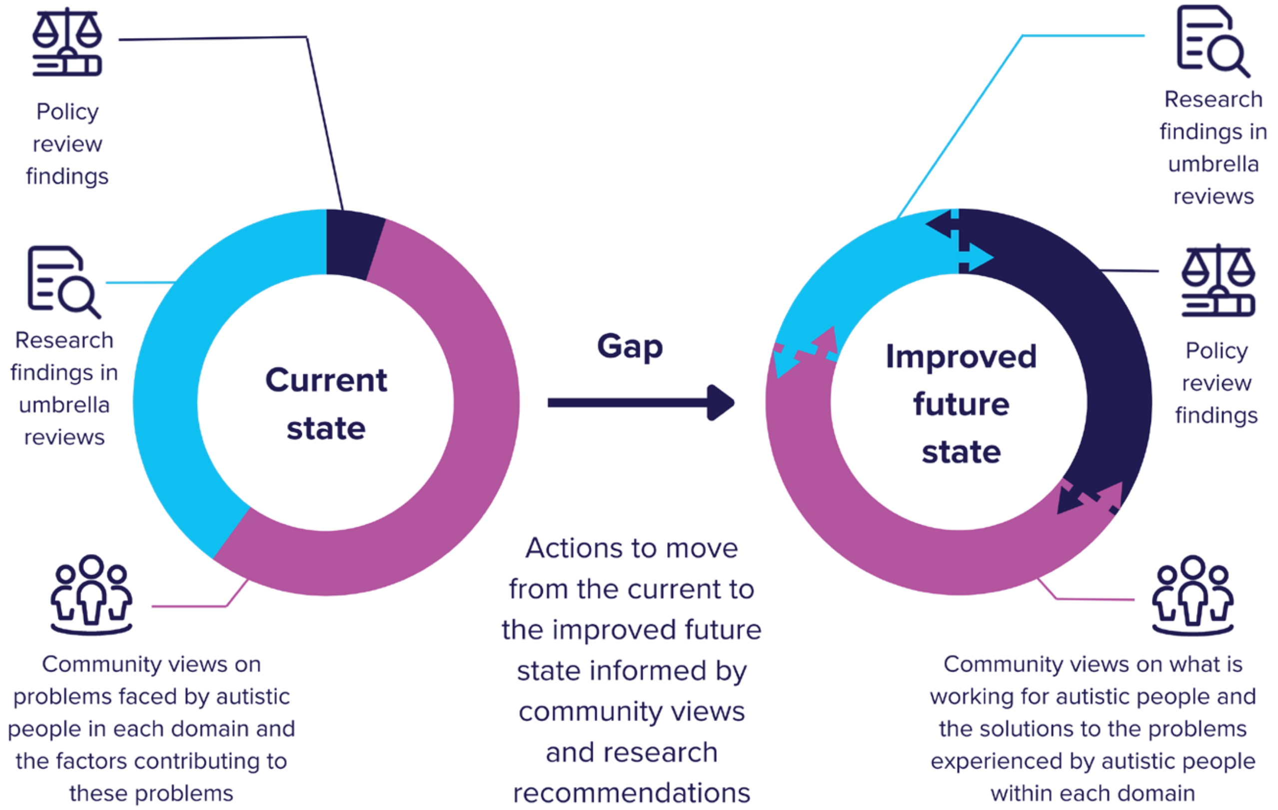
Organisation name	Policy name	Reference to autism	Reference to disability	Relevant information
State Government (WA)	State Planning Policy 7.0 Design of the Built Environment (2019)	✗	✓	• New developments should have some capacity to adapt to changing uses and demographics, such as an ageing population and people with disability.
State Government (SA)	Inclusive SA; State Disability Plan (2019-2023) The Community housing disability access and inclusion policy	✗	✓	• Integrating Universal Housing Principle in all social housing • Investment into 100 houses for use by community housing providers • Providers to have trained staff, necessary systems in place, and well-developed networks to support customers.
Territory Government (NT)	Northern Territory Disability Strategy (2022-2032) Northern Territory Housing Strategy (2020-2025)	✗	✓	• Increase the availability of housing that meets universal design principles, including urban and rural/ remote stock • Specialist Disability Accommodation to be developed and designed for people who require a specialised housing solution that can assist with the delivery of supports.
State Government (VIC)	Inclusive Victoria State Disability Plan (2022-2026)	✗	✓	• Mandated the "silver" Liveable Housing Design Guidelines as the minimum accessibility requirements in Victoria for new social housing and collaborates with the building and construction industry and disability advocates to transition • Prioritises affordable, stable, secure, and suitable housing for people requiring supported living, considering the principles of choice and control • The 10-Year Strategy for Social and Affordable Housing commenced but not completed by predicted 2022.
State Government (VIC)	Victoria Autism Plan (2019)	✓	✓	• For people with disability to have housing choices that are flexible, suitable, affordable, and accessible • Respond to the housing needs of autistic Victorians • A better understanding of the housing challenges for autistic people needed to drive greater oversight and accountability.

Organisation name	Policy name	Reference to autism	Reference to disability	Relevant information
State Government (TAS)	Accessible Island Tasmania's Disability Framework for Action (2018-2021) Tasmania's Affordable Housing Action Plan (2019-2023)	×	✓	• To increase the supply of public and social housing properties with accessible design features • Dedicated investment to deliver more suitable homes to NDIS participants, including regional and rural areas • Assess needs of people with chronic mental illness and construct homes to ensure secure lease terms and the clinical support required to sustain their home.
State Government (QLD)	All Abilities Queensland: Opportunities for All State Disability Plan (2017-2020) The Queensland Housing Strategy (2017-2027) The Queensland Housing and Homelessness Action Plan (2021-2025)	×	✓	• Ensuring people with disabilities exercise rights and control over their housing and community participation, promoting rights, choice, control, accessibility. and inclusion • Partnering with real estate, agencies, and key groups for inclusive housing responses that support vulnerable tenants, including those with disabilities • Co-design housing responses with people with disabilities • Recognising the increased vulnerability to disasters, abuse, and neglect affecting housing options.
State Government (NSW)	Better Placed: An integrated design policy for the built environment of New South Wales (2017)	×	✓	• A well-built environment is equitable (inclusive and accessible public spaces).

3.5.4 Community views, research evidence, and policy/guideline alignment and gap analysis

In addition to the research gaps identified as part of the research landscape mapping, a comprehensive gap analysis was conducted (see Figure 6 for process). The gap analysis provides a comparison between the *current state* (predominantly based upon the community views analysis but also some findings of the umbrella review and policy review) and an *improved future state* (based upon community views around what is working well, policy review, and some umbrella review findings).

Figure 6: Gap analysis: Current to improved future state



The gap analysis for the housing and independent living section puts into focus steps that can be taken to better meet the housing needs of autistic people.

3.5.4.1 There needs to be improved housing accessibility for autistic people

Current state

The **community** views survey indicated that autistic people face a number of challenges when trying to access housing. The primary issue noted was related to a lack of adequate support or government funding to get or sustain housing. This was explained in the context of long wait times for public housing and high rates of unemployment among autistic people which prevents them from being able to independently afford housing. The **community** views survey also pointed out that autistic people experience difficulty navigating the government systems and rental processes which become barriers to their ability to access housing. There was an absence of **research** identified in the umbrella review that considered accessibility of housing for autistic people; however, it is clear that this is a central concern for autistic people.

Improved future state

The **community** views survey indicated that rent assistance, disability housing with supports, and providing flexible funding that addresses individual circumstances work well for autistic people. Multiple **policies** specified the provision of housing support that is tailored for people with disabilities. "Australia's Disability Strategy" (2021) document in the **policy** review indicated the need to increase housing availability and affordability for people with disability. However, among the government policies reviewed, only two spoke to housing in relation to autistic people. The Australian Government response to the Select Committee on Autism (report): Services, support and life outcomes for autistic Australians specifically addressed the housing needs of autistic people and spoke to the need for government agencies that provide funding support for housing, such as the NDIS, to consider the informal burden of care on parents and independent living options available to autistic people. Furthermore, the "Victoria Autism Plan" (2019) outlined the need for a better understanding of the housing needs of autistic people to be able to improve oversight and accountability in aligned government bodies.

Steps that can be taken to move from the current to the improved future state include:

- Further consultation with the autistic community to identify the specific challenges that autistic people experience with accessing housing to enable simplifying processes and identifying ways that funding support can be made more flexible to better meet their housing needs.
- Co-developing (developing along with the autistic people and autism communities) autism-specific pathways for housing access for autistic people with varying levels of support needs.
- Government initiatives to address general rental shortages (relevant to, but not specific to, the autistic community).

3.5.4.2 There needs to be more education across government and non-government agencies and bodies about autism and the needs of autistic people

Current state

The **community** views survey revealed that many of the challenges autistic people experience related to accessing housing are due to a lack of awareness and understanding of autism and the needs of autistic people and what works for them. This results in autistic people feeling that government policies and decisions are inadequate in meeting their needs as they are made without consideration of their needs and experiences. It also results in autistic people feeling that they are stigmatised and discriminated against in the rental market. The **research** landscape mapping results align with the community views, also indicating that there is a lack of co-produced research that focuses on the needs, perspectives, and experiences of autistic people as it relates to housing.

Improved future state

The **community** views survey indicated that having housing staff in government and non-government agencies that understand autism and the needs of people with autism would help to reduce the problems autistic people experience with housing. The community views survey also highlighted that having partnerships with autism specialised support, and support to assist with securing and sustaining private housing, would be very beneficial to autistic people. None of the **policies** in the policy review directly addressed autism training needs of personnel in housing agencies. However, the **community** views survey highlights that this is an important step to be able to improve the experiences and housing outcomes for autistic people.

Steps that can be taken to move from the current to the improved future state include:

- Co-creation (where the autistic community equally collaborates and contributes) of evidence-based autism-specific training that is tailored towards professionals in the housing space including government bodies as well as rental estate associations or networks
- Provide rights-based training for autistic people that will sensitise them to their rights and responsibilities regarding housing and tenancy. This should include outlining rental processes, expectations and rights related to home maintenance and home inspections
- Provide assistance that supports autistic people to better understand rental contracts/agreements and better navigate private rental processes
- Increase awareness and advocacy for autistic people in the housing sector among government and non-government bodies to foster understanding of autism and aid in autistic people securing private housing.

3.5.4.3 There needs to be more suitable housing options for autistic people

Current state

The **community** views survey highlighted that there is a lack of suitable housing options for autistic people that meet their various needs. Many autistic people have specific needs relating to building layout, sensory exposure, safety, and personal space. However, the community views survey revealed that there is an absence of available public housing designed specifically to meet the needs of autistic people. These challenges extend to the private rental market that often has strict rules prohibiting tenants from having pets or making modifications to properties. These restrictions prevent autistic people from making adaptations to their living spaces to meet their needs.

The **research** landscape mapping supports the community views that speak to the needs of autistic people. It highlighted that autistic people may have varying levels of sensory sensitivities and suggested a number of considerations that can be made to building and residential design that can best accommodate them. Additionally, it pointed out the need for experimental practice and policies that foster inclusion of autistic people in the design processes of residential and urban spaces of which they will be users, and monitoring of these outcomes for sustainability.

Improved future state

The **community** views survey highlighted that having regulations that allow autistic people to make subsidised changes to their homes is one way to reduce the problems they experience with suitable housing. All the **policy** documents reviewed discuss the need for suitable housing accommodations for people with disability. However, only the “Australian Government Response to the Select Committee on Autism (report): Services, support and life outcomes for autistic Australians” policy review outlines the need for improved suitability of housing that accommodates the varying sensory, physical, and intellectual needs of autistic people.

Steps that can be taken to move from the current to the improved future state include:

- Co-design and consultation with the autistic community (with autism community involvement and contribution) related to suitable residential design for new public housing accommodations for which they will be users. Michelle Dival’s Churchill Fellowship report (2017) offers a thorough examination of informed neurodiverse housing and design, complete with clear guidelines that could help government bodies, industry organisations, and private housing providers better understand and allow for such choice (churchilltrust.com.au/fellow/michelle-dival-wa-2017/)
- Further consultation with the autistic community and other relevant stakeholders regarding a scope of practical modifications that may be permissible in the context of private rental accommodations that can be used for legislative purposes
- Increase advocacy and accountability measures that ensure that policy guidelines related to access to suitable housing are upheld
- Consideration for housing design should take into consideration the wider living environment and issues that relate to accessibility for autistic people.

3.5.4.4 Autistic people need to have more options and choice about the type of living arrangement that will work best for them

Current state

The **community** views survey highlighted that autistic people feel that they have few options and little choice in their living arrangements. Specifically, there are a lack of options for autistic people to live independently outside of shared housing or with family. The community views survey indicated that autistic people may experience challenges to safety and well-being in shared housing, yet may lack the support they need and/or financial resources to live alone. The **research** landscape mapping also showed a lack of research exploring the needs and experiences of autistic people living in various residential settings and the specific skills autistic people need to live in each setting, such as in shared housing or on their own.

Improved future state

The **community** views survey highlighted that housing arrangements work well for autistic people when they have a choice in where they live and have independent living support. Multiple **policies** in the policy review indicated that people with disabilities have a right to choose where they live and that, as much as possible, housing arrangements should accommodate the preferences of individuals. However, only the “Australian Government Response to the Select Committee on Autism (report): Services, support and life outcomes for autistic Australians” policy initiative gave direct consideration to autistic people’s need for choice in living options to affirm their autonomy and right to self-direction.

Steps that can be taken to move from the current to the improved future state include:

- Further consultation with the community to explore the independent living needs of autistic people. These findings can be used to inform strategies to improve independent living skills of autistic people as well as to identify specific types and levels of support that autistic people need to live independently
- Co-development (developing along with the autistic people and autism communities) of autism-specific pathways for different housing options, including living alone. This should take into consideration various levels of independent living support available and be built using a needs and feasibility approach.

3.5.5 Umbrella review: Independent living

The research team, in recognising the gap in information related to the independent living in the housing component of the section, undertook an umbrella review to bring into focus existing research reviews (systematic and scoping) on this specific topic. The search terms used, and the number of articles identified, screened, and included, are provided in Appendix H-5. Eighteen systematic reviews were included in this umbrella review; none were led by Australian authors and 10 (56%) were conducted in the last 5 years. There were 353 individual studies reported across the 18 reviews.

The summarised findings and information from included studies can be found in the subsections below. When reporting on the number of people or participants in the review, this will be represented as *n* = [number of participants]. When reporting on the number of reviews that considered a topic, this will be represented as *k* = [number of reviews].

3.5.5.1 Participants within included reviews

Fourteen reviews reported on the number of participants, which represent a total of 1,042 with sample sizes in individual studies ranging between one and 50 participants. Of these participants, 919 were reported to be autistic. Only nine reviews provided information on the gender of autistic participants; most were male (average percentage = 79.2%) and ranged in age from 2 to 55 years.

3.5.5.2 Quality of included reviews

The quality of the included systematic reviews was assessed using the JBI Critical Appraisal Tool for Systematic Reviews. This tool assesses the methodological quality of a systematic review. The maximum score is 33, which indicates a very high-quality systematic review. The average quality score for the 18 included systematic reviews was 27 (81.8%), with the quality score ranging from 18 to 33.

3.5.5.3 Topics of included reviews

The findings of the 18 systematic reviews identified in the area of autism and independent living can be summarised into three key topics. These were strategies for teaching independent living skills to autistic people (*k* = 18), under-researched aspects of independent living skills (*k* = 7), and under-researched populations (*k* = 11). The key findings for each topic are discussed in Table 34.

3.5.5.4 Research gaps

All of the included reviews were conducted on intervention research to assess the effectiveness of various strategies to teach independent living skills to autistic people. Across the systematic reviews, several research gaps were identified and combined with other research gaps identified by the authors. These research gaps are summarised in Table 34.

It is noteworthy that none of the reviews identified under the umbrella review for independent living were conducted in Australia. This indicates a large research gap within the autism research space. The review indicates that a wide range of intervention strategies and designs have been found to be successful in teaching independent living skills to autistic people, with video-based instruction leading as the most common strategy being employed across the literature. Caregiver and peer-implemented interventions were also found to be promising in teaching independent living skills. However, across the body of research, there was a lack of consistency in definition and type of independent living skills being taught, as well as inconsistency in outcome measures and methodological quality across studies. This poses challenges to drawing conclusions and confirming best practices for interventions in this domain.

Another notable limitation in the review is the lack of evidence related to the maintenance and/or generalisation of independent living skills captured in research studies. This also limits the generalisability of the findings as there is a lack of conclusive evidence that acquired skills lead to long-term improvements in daily functioning. Consequently, there is a need for more high-quality research that targets the core independent living skills needed for navigating daily life and that embeds mechanisms to assess maintenance and skill generalisation into the design and reporting process. There is also substantial need for research that includes females, adults, and autistic people from diverse backgrounds to more holistically assess intervention strategies that work best across populations or that are specific to certain populations.

Table 34: Umbrella review findings for independent living

Topic	Number of reviews on topic; citations	Key findings	Key research gaps identified
Strategies for teaching independent living skills to autistic people	k = 18 (Aljehany & Bennett, 2019) (Auld et al., 2022) (Bennett & Duke, 2014) (Flynn & Heely, 2012) (Hong et al., 2017) (Hong et al., 2016) (Hrabal et al., 2022) (Kirby, 2016) (Marcotte et al., 2020) (McGinnis et al., 2023) (Munsell & Coster, 2021) (Neely et al., 2016) (Palmen et al., 2012) (Skjoldborg et al., 2022) (Syriopoulou–Dell & Sarri, 2022) (Taconet et al., 2023) (Wertalik & Kubina, 2017) (Yakubova & Baer, 2022)	• The most common independent living skills across the literature were housekeeping (cleaning, washing, laundry skills, etc.), self-help skills (meal preparation), social skills (initiating and engaging in social interaction, understanding social cues, etc.) and practical skills (money management, time management, navigation, etc.) • A wide range of intervention modalities are effective in teaching independent living skills to autistic people to increase their autonomy • Teaching strategies for independent living skills largely incorporated prompting in various forms (video, auditory, gestural, hand-over-hand, or least-to-most prompting) • The use of video-based instruction has emerged as a dominant modality for teaching independent living skills • The use of technology-based interventions such as video modelling and video prompting has demonstrated positive outcomes in teaching independent living skills: • Multiple diagnostic categories: autism, autism and intellectual disability, and cognitively “high-functioning autism” or Asperger syndrome – Age groups: young children to adults – Video modelling is moderately effective for teaching employment skills, house chores, and community access skills to autistic adolescents and adults and strongly effective for teaching self-help skills – Video modelling and video prompting are well accepted as an intervention method by autistic adolescents as it allows greater autonomy and decreases the need for human intervention providers – Video modelling and video prompting are effective when used as a specific intervention modality, as well as when combined with other strategies – Video-based instruction demonstrates positive results for skill maintenance and generalisation – Technology tools are versatile and can be used to teach multiple skills; for example, a tablet can show videos, provide an app for scheduling activities, and a budgeting app for expenses	• Most research conducted in school settings where skills are not applicable. There is a need for intervention research conducted in natural and community settings • Future research should evaluate generalisation of acquired skills continuously, particularly in the natural setting • Additional research should continue to explore the effectiveness of technology such as smartphone or tablet applications, audio prompts, videoconferencing, visual schedules, and augmented or virtual reality to teach independent living skills as an incorporation in the daily living practices of autistic adults • Co-design of interventions with the autistic and autism community that will facilitate the optimising of integration of interventions into daily living and improve outcomes • There is a lack of methodologically strong designs in the area of virtual reality via head-mounted display to provide firm conclusions about its effectiveness • There is a need for more research with bigger sample sizes to improve generalisability of findings related to outcomes • Future studies should examine the level and type of training necessary to train parents to implement video-based instruction as primary agents of change versus complementary agents of change • There is a need for more group design studies that can increase the generalisability of findings

Topic	Number of reviews on topic; citations	Key findings	Key research gaps identified
		• Peer-mediated intervention (PMI), which involves training peers to act as intervention agents that implement instructional programs and teach self-help and social skills and behaviours, was identified as being very effective • Caregiver-implemented interventions also improve outcomes for autistic individuals: – Caregivers rate these interventions as being high in social validity and implement interventions with high fidelity to outlined intervention protocols – Behaviour skills training (i.e., written or verbal instructions, modelling, rehearsal, and feedback) were key components of the training package for caregivers conducting these interventions – The inclusion of caregivers in the development of independent living skills interventions can increase adherence to procedures – Caregiver-implemented interventions occur in natural settings where skills can be used, generalised, and maintained through practice in the everyday context • Interventions using virtual reality technology using head-mounted display suggest general positive outcomes on target independent skills such as handling money, shopping skills, and riding the bus. This technology may show promise in advancing the teaching of independent living skills through: – The use of sensory input adjusted scenarios based on the individual's needs, or through the gradual increase of difficulty in the learning scenario – Its ability to be manipulated in real time. Participants are able to replay the same scenario and implement changes in behaviour in response to the scenario and observe effects and outcomes – Its flexibility for individualised design and implementation – Further research should explore the potential advantages of modulating sensory stimuli and adjusting task difficulty to improving learning outcomes as well as personalised design to improve outcomes Interventions conducted in natural settings yield more positive outcomes relating to generalisation and maintenance of skills than those conducted in contrived settings – High school special education services that taught independent living skills are positively predictive of adult employment and independent living outcomes	• Future comparative research that examines virtual reality head-mounted display interventions to other intervention modalities to determine relative effectiveness • More research that includes an assessment of improvements in life skill in real-world settings along with follow-up assessments. This would allow for firmer conclusions regarding the ability of autistic individuals to successfully transfer skills acquired within the virtual learning environment to the real world • Additional replication studies needed that assess the effects of social validity on video-based instruction with diverse samples • Future studies using caregiver implemented interventions need to include specific, detailed description of parent training methods, parent characteristics, and child demographic information and autism characteristics to improve generalisability

Topic	Number of reviews on topic; citations	Key findings	Key research gaps identified
Under-researched aspects of independent living skills	*k* = 7 (Auld et al., 2022) (Bennett & Duke, 2014) (Flynn & Heely, 2012) (Hong et al., 2017) (Hrabal et al., 2022) (Neely et al., 2016) (Taconet et al., 2023)	• Self-help skills, house chores, safety skills, and skills related to accessing the community are largely absent from the independent living research • There is limited research targeting personal care skills such as grooming, hygiene, and dressing as areas of focus for independent living skills. This is notable as challenges with dressing, grooming, and hygiene are particularly prevalent among autistic individuals • Very few studies included the subjective experience of autistic individuals and their families about perceived barriers and enablers to acquiring independent living skills. A thorough understanding of perceived barriers and enablers to skill acquisition can result in interventions that are customised and better suited to meet the needs of autistic people	• More focus on independent living skills that focus on core skills needed for autistic people to improve their independent functioning • More research should position parent as implementer of interventions to enhance application of independent living skills in daily living • Future research that explores the enablers and barriers to acquiring independent living skills among autistic people and their families • Need for more replication studies that can serve to improve the generalisability of their conclusions • More research designed to measure and assess generalisation and maintenance of acquired skills over medium to long term
Under-researched populations	*k* = 11 (Aljehany & Bennett, 2019) (Bennett & Duke, 2014) (Flynn & Heely, 2012) (Hong et al., 2016) (Kirby, 2016) (Marcotte et al., 2020) (McGinnis et al., 2023) (Munsell & Coster, 2021) (Palmen et al., 2012) (Taconet et al., 2023) (Wertalik & Kubina, 2017)	• Current research mainly done with autistic males and not representative of females or other gender identities • Most of the independent living skills research is conducted with children and adolescents. There is a need for more research among the adult population • There is limited research on teaching independent living skills to young autistic adults with low support needs; however, one review indicated that behavioural interventions can be successfully used to improve adaptive skills among this group, particularly around improving task engagement • There is a paucity of research on teaching independent living skills to autistic people with a diagnosis of severe or profound autism • There is a paucity of independent living research related to autism that incorporates or reports on diversity in participant characteristics such as ethnicity, co-morbidities (physical and mental health), and socioeconomic status	• Research should report on basic participant characteristics such as age and gender • More research that considers the independent living skills needs of students at the post-secondary education level • Need for more studies that include autistic adolescents/youth in the development of intervention or goal-selection process to increase the social validity of interventions

3.6 Justice

3.6.1 The “1,000 Insights” community views survey

A total of 166 respondents answered at least one of the questions on the justice system. This included 86 autistic people and 110 family members or carers of autistic people. The 10 most frequently reported responses are reported within this section.

The tables for each question describe the response categories (with example participant responses) in order from the most frequently reported to the least frequently reported. For each category, percentages are provided to indicate the proportion of a respondent group whose response reflected the specific category. These groups are: (a) the entire sample (i.e., everyone), (b) autistic people, (c) family members/caregivers of autistic people, and (d) all respondents who are not represented in one of these groups.

3.6.1.1 Problems experienced by autistic people in relation to the justice system

A total of 166 respondents opted to answer this question on the justice system. This included 86 autistic people and 110 family members or carers of autistic people. The problems experienced were coded into nine categories, which fall under the following six broad areas:

- Lack of autism-specific knowledge, awareness, and understanding of professionals in the justice system
- Adjustments and accommodations not offered or supported within the justice system for autistic people
- Autistic language and communication styles or preferences not accounted for or misinterpreted
- Autistic people feeling scared of, dismissed by, or experiencing discrimination from those in the justice system
- Lack of consideration about how autism may be a factor in how a person became a victim and/or committed a crime
- Limited identification of autism and/or co-occurring conditions.

Table 35 ranks the nine problems that autistic people experience in relation to the justice system (based on the survey responses). The data are ranked from most frequently reported to least frequently reported problems across all respondents. The right-hand columns report the proportion of specific respondent groups that identified this as a problem. Note that respondents often identified within multiple groups (e.g., autistic and a parent/caregiver of an autistic child), so the number of respondents in subgroups exceeds the total number of all respondents.

Of note is that these data show that approximately:

4 in 10 respondents highlight that professionals in the justice system have a poor understanding or knowledge of autism and how it presents in different people or contexts.

1 in 4 respondents highlight that the justice systems or settings (including physical or sensory settings) are not supportive for autistic people, sometimes leading to an inability to function or cope.

1 in 5 respondents highlight that characteristics of autism or the behaviour of autistic people (including meltdowns and shutdowns) are misinterpreted or treated as a criminal issue.

Table 35: 9 most frequently reported problems experienced by autistic people in relation to the justice system

Rank	Problems experienced by autistic people in relation to the justice system and sample quotes from responses	Direct insight	% who stated this as a problem			
			All respondents *N* = 166	Autistic people n = 86	Family member/ caregiver of autistic person n = 110	Other respondent groups* n = 94
1	**Poor understanding or knowledge of autism and how it presents in different people or contexts** (e.g., specific presentations of autism, and variability in autism profiles, are not understood)	*"Professionals in the justice sector having extremely inaccurate ideas about what autism is and how autistic people might function or present in a given context."* (ID 195) *"Appalling understanding in fact (I am a Dr/GP working in justice health) in that even the forensic psych have little awareness."* (ID 448)	39%	37%	46%	35%
2	**Justice systems or settings (including physical or sensory settings) not supportive for autistic people, sometimes leading to an inability to function or self-regulate** (e.g., justice system contexts like courtrooms are overwhelming on a sensory level; processing and responding to complex information under stress is very difficult for autistic people)	*"Autistic victims of crime may have more difficulty describing their experiences to police due to their sensory/social needs not being accommodated."* (ID 290) *"The rigid structure of the justice system often does not accommodate the needs of an autistic person. They often need a lot of support to stay involved. The drawn out process of a judicial case can be very traumatic for an autistic person, to the point that they will not continue to participate."* (ID 1511)	24%	22%	20%	21%
=3	**Characteristics of autism or autistic behaviour (including meltdown, shutdown) misinterpreted or treated as criminal issue** (e.g., minimal eye contact viewed as sign of guilt)	*"Meltdowns perceived as defiance and aggression."* (ID 381) *"My brother used to have a lot of issues with the local police because they didn't understand his behaviours were the result of autist meltdowns."* (ID 935)	22%	23%	22%	21%

Rank	Problems experienced by autistic people in relation to the justice system and sample quotes from responses	Direct insight	% who stated this as a problem			
			All respondents *N* = 166	Autistic people n = 86	Family member/ caregiver of autistic person n = 110	Other respondent groups* n = 94
=3	**Adjustments or accommodations not offered or system not taking into account needs of autistic people** (e.g., lack of access to advocates experienced in supporting needs of autistic people; lack of support during police interviews; lack of clearly communicated information)	*"Lack of support to provide us with legal info, legal advice and support through am [sic] end to end legal process."* (ID 1085) *"Lack of access to independent advocates who are experienced with the support needs of autistic people."* (ID 1159)	22%	24%	24%	22%
5	**Autistic language and communication styles or preferences not accounted for or misinterpreted** (e.g., autistic people's communication style/needs not respected or heard)	*"Police and courts not being able to talk at their level of understanding and mistaking not understanding questions asked as lying."* (ID 528) *"Not being heard or understood by law enforcement and the justice system."* (ID 1004)	20%	20%	23%	26%
6	**Autistic people feeling scared of, dismissed by, or experiencing discrimination from those in justice system** (e.g., being treated as having less rights than non-autistic people; not getting a fair say/fair defence)	*"The fear that professionals instil into people with Autism."* (ID 1303) *"Rights and interests are not addressed or even recognised."* (ID 1436)	18%	23%	16%	23%
7	**Autistic people may not understand laws or legal or justice system** (e.g., autistic people may not understand legal systems/processes; may not understand, or may have a different perspective of, what they have done)	*"Not really knowing what [it's] all about. Others thinking the person with autism does understand [what's] happening when they engage with justice system when they do not or at least not fully."* (ID 1093) *"They could be misled by the police into a false confession because they are easily led, want to please and may believe it if the police inform them they do not need a lawyer."* (ID 1172)	12%	12%	16%	14%

Rank	Problems experienced by autistic people in relation to the justice system and sample quotes from responses	Direct insight	% who stated this as a problem			
			All respondents *N* = 166	**Autistic people** n = 86	**Family member/ caregiver of autistic person** n = 110	**Other respondent groups*** n = 94
8	**Increased risk of entering criminal justice system including through manipulation, coercion, or not fully understanding the implications of an act** (e.g., autistic people's trust may mean they do not recognise when they are victims of, or committing, crime)	*"People with autism are being manipulated and coerced by criminals to commit crimes they have no understanding of - even if they have high IQ. I have a university degree but was naive when someone asked me to hold a brown paper bag full of drugs. He told me there was 'stuff' in the bag and I believed him. It was only when I told the story to someone else they told me it was illegal and I could have been convicted of assisting with drug dealing."* (ID 60)	10%	11%	6%	9%
9	**Limited identification or understanding of undiagnosed autism and/or co-occurring conditions** (e.g., behaviours of undiagnosed autistic people may be misinterpreted as criminal; lack of understanding around higher incidence of mental health challenges in autistic population)	*"Lack of understanding of co-occurring conditions."* (ID 910) *"[Many] incarcerated people would qualify for a diagnosable mental health 'disorder' many are undiagnosed neurodivergent."* (ID 974)	7%	11%	6%	9%

Note. *all other groups that have not been identified separately

3.6.1.2 Factors causing the problems experienced by autistic people in relation to the justice system

A total of 124 respondents opted to answer this question on the justice system. This included 64 autistic people and 89 family members or carers of autistic people. The factors that respondents felt were causing or leading to the problems experienced by autistic people within the justice system were coded into eight categories, each falling under their own broad area:

- Lack of autism training/education to enhance knowledge, minimise misinterpretations, or address stigma/assumptions
- Limited adjustments or accommodations provided to autistic people accessing the justice system
- Funding limits access to supports and services for autistic people accessing the justice system
- Issues relating to the policy, laws, and systemic factors governing the justice system
- The justice system is based on neurotypical norms and expectations
- Many people within the justice system are undiagnosed autistic and there is no pathway to receive a diagnosis within justice system
- Autistic people experience ableism and other forms of discrimination/indifference from those in justice system
- Autism characteristics may increase vulnerability to becoming involved in justice system.

Table 36 ranks the eight most commonly reported factors that respondents felt were causing the problems that autistic people experience in relation to the justice system. The data are ranked from most frequently reported to least frequently reported problems across all respondents. The right-hand columns report the proportion of specific respondent groups that identified this as a problem.

Importantly, these data show that approximately:

3 in 5 respondents stated that the problems were due to the lack of autism training/education to enhance knowledge, minimise misinterpretations, or address stigma/assumptions.

1 in 5 respondents reported that the problems were due to limited adjustments or accommodations provided or available to autistic people accessing the justice system.

Table 36: 8 most frequently reported factors causing the problems experienced by autistic people in relation to the justice system

Rank	Factors causing the problems experienced by autistic people in relation to the justice system and sample quotes from responses	Direct insight	% who stated this as a problem			
			All respondents *N* = 124	Autistic people n = 64	Family member/ caregiver of autistic person n = 89	Other respondent groups* n = 49
1	**Lack of autism training/education to enhance knowledge, minimise misinterpretations, or address stigma/assumptions** (e.g., lack of training for police on autism; lack of understanding/awareness of autism within the justice system)	*"Police are improperly trained regarding interactions with autistic people and misidentify autism symptoms as drug use or uncooperative behaviour."* (ID 81) *"Lack of training regarding neurodivergent needs and accommodations."* (ID 1471)	57%	61%	58%	69%
2	**Limited adjustments or accommodations provided or available to autistic people accessing the justice system** (e.g., adjustments not made in prisons and courts; lack of safe spaces away from crowds)	*"Disability rights and reasonable adjustment not being applied consistently throughout Australia's justice systems."* (ID 937) *"Sensory overload. For example physical contact from strangers being unpleasant and uncomfortable for people with Aspergers."* (ID 1481)	19%	23%	20%	18%
3	**Funding limits access to supports and services for autistic people accessing the justice system** (e.g., Legal Aid is busy and has too many cases to get through)	*"Not having full legal aid help available here in Australia for low-income earners."* (ID 153)	15%	17%	17%	16%
4	**Policy, laws, and systemic issues governing the justice system** (e.g., the justice system does not listen to the community)	*"Lack of desire to be inclusive. A culture of exclusion and suppression of marginalised groups."* (ID 195) *"Systemic disrespect for anyone in trouble with the law – treated like a 'criminal' even before trial and it is very distressing for a person with autism."* (ID 897)	13%	13%	11%	10%

Rank	Factors causing the problems experienced by autistic people in relation to the justice system and sample quotes from responses	Direct insight	% who stated this as a problem			
			All respon-dents *N* = 124	Autistic people n = 64	Family member/ caregiver of autistic person n = 89	Other respondent groups* n = 49
5	**Justice system is based on neurotypical norms and expectations** (e.g., concepts of criminal or untrustworthy behaviour are centred on neurotypical norms; the structure of the justice system is designed for neurotypical/male people; justice system doesn't cater for those who struggle with self-advocacy/ communication)	*"Neurotypical bias of systems, processes, policies, expectations."* (ID 699) *"Neurotypical world view which feeds stigma and discrimination against autistic people. For example, in a court room, an autistic person giving evidence may not give eye contact, look around, have pauses between questions, answer questions without hearing them and require questions be repeated. Neurotypical people in a jury could view these behaviours as showing the witness is untrustworthy, not telling the truth etc."* (ID 873)	10%	9%	9%	6%
6=	**Undiagnosed autism and no pathway to receive a diagnosis with justice system** (e.g., lack of diagnosis of autism; lack of diagnosis of co-occurring conditions)	*"Law enforcement is not equipped to deal with undiagnosed disabilities such as ASD."* (ID 60) *"[Autism] assessment of people in judicial system is flawed and inadequate."* (ID 1499)	7%	6%	8%	2%
6=	**Autistic people experiencing ableism and other forms of discrimination/indifference from those in justice system** (e.g., discrimination of those with intersectional identities; police aggression)	*"Systemic issues and intersectional discrimination."* (ID 637) *"Police too aggressive and not listening (I have physical bruises and cuts)."* (ID 1475)	7%	11%	5%	6%
8	**Autism characteristics may increase vulnerability to becoming involved in justice system** (e.g., criminals identify autistic people as gullible and exploitable; autistic people can experience grooming and predatory behaviour)	*"Vulnerability to social isolation and malicious group influences."* (ID 492) *"Not being able to differentiate between who is a 'good' friend and who is a 'bad' friend."* (ID 1212)	6%	9%	5%	4%

3.6.1.3 Factors that could prevent or reduce the problems experienced by autistic people in relation to the justice system

A total of 128 respondents opted to answer this question on the justice system. This included 60 autistic people and 88 family members or carers of autistic people. The factors that respondents identified as preventing or reducing the problems experienced by autistic people within the justice system were coded into eight categories. These categories fall under the following six broad areas:

- Enhancing autism-specific knowledge, awareness, and understanding of professionals in the justice system and broader community
- Providing supports, adjustments, and accommodations within the justice system for autistic people
- Making amendments to the policy, law, and systemic issues governing the justice system to take into consideration autistic people
- Support the acceptance and awareness of autism within the broader community/society
- Consultation with autistic/neurodivergent people to ensure the justice system is appropriate for autistic people
- Develop a means to better identify that a person is autistic (e.g., through assessment and diagnostic services within the justice system and more broadly; identification cards).

Table 37 ranks the eight most commonly reported factors that respondents reported could prevent or reduce the problems that autistic people experience in relation to the justice system. The data are ranked from most frequently reported to least frequently reported problems across all respondents. The right-hand columns report the proportion of specific respondent groups that identified this as a problem.

Importantly, these data show that there was a clear, predominant factor highlighted by respondents:

Nearly 2 out of every 3 respondents stated that training in autism could prevent or reduce the problems experienced by autistic people in relation to the justice system.

Table 37: 8 most commonly reported factors that could prevent or reduce the problems experienced by autistic people in relation to the justice system

Rank	Factors that could prevent or reduce the problems experienced by autistic people in relation to the justice system and sample quotes from responses	Direct insight	% who stated this as a problem			
			All respon-dents *N* = 128	Autistic people n = 60	Family member/ caregiver of autistic person n = 88	Other respondent groups* n = 77
1	**Provide education/training to improve awareness, understanding, and knowledge of autism, associated characteristics, and how to work with/ support autistic individuals in the justice system** (e.g., knowledge of how to respond to autistic people; training for police)	*"We need to provide more education to lawyers, [m] agistrates, barristers and anyone else involved in the justice system around autism and how we could be better supported during what most likely could be the lowest point in our lives as victims or accused."* (ID 400) *"Education and professional support about what it means to live with autism, how to communicate effectively with people with communication difficulties, and the implication of living with sensory issues and other factors that impact behaviour and experience in the world."* (ID 1308)	63%	65%	66%	58%
2	**Improve access to appropriate and sufficient supports across areas (i.e., social supports, legal supports, other professional supports, mental health, written information)** (e.g., extra time to process questions; not needing to attend court in person; access to support people)	*"Disabled people should automatically be granted [...] a case worker/social worker to help them understand what is happening."* (ID 81) *"Provision of information pamphlets with photos of the court environment and information about procedures. Provision of an information pamphlet explaining procedures when police are involved e.g., witness interview, what happens when arrested, explain protective custody."* (ID 1546)	20%	19%	17%	17%
3=	**Amendments needed to the policy, laws, and systemic issues governing the justice system** (e.g., policy reform to be more inclusive of difference; reform to state discrimination laws)	*"Severe punishments for those that use force against autistic meltdowns."* (ID 277) *"Law reform and embedded processes on recognising and understanding ASD in the legal system for both criminal and civil matters."* (ID 616)	15%	19%	16%	16%

Rank	Factors that could prevent or reduce the problems experienced by autistic people in relation to the justice system and sample quotes from responses	Direct insight	% who stated this as a problem			
			All respon-dents *N* = 128	Autistic people n = 60	Family member/ caregiver of autistic person n = 88	Other respondent groups* n = 77
3=	**Foster the use of an individualised approach and accommodation of individual needs** (e.g., use of interpreters when communication is difficult)	*"Well we've busted our a**es in recent years trying to mitigate [state police] responses to my son's incidents by application for an interagency response team of [state ambulance services] and [state police] in a tiered response plan to attend the house instead of [supported independent living] staff calling [state police] alone for emergency assistance when negotiation between my son and his staff fails (2:1)."* (ID 1119)	15%	15%	17%	16%
5	**Develop ways to positively impact broader community/societal factors that increase autism acceptance or awareness** (e.g., more widespread information about autism; public education about autism)	*"Education including community awareness program."* (ID 47)	10%	9%	9%	10%
6	**Ensuring the perspectives of autistic people are included in training/education or decisions about the justice system** (e.g., education about autism from neurodivergent/ autistic individuals; including the perspectives of autistic people in police training)	*"Voice of autistics in police training and ongoing learning."* (ID 1127) *"Education and training from Autistic led organisations."* (ID 1512)	8%	7%	6%	8%

Rank	Factors that could prevent or reduce the problems experienced by autistic people in relation to the justice system and sample quotes from responses	Direct insight	% who stated this as a problem			
			All respon-dents *N* = 128	Autistic people n = 60	Family member/ caregiver of autistic person n = 88	Other respondent groups* n = 77
7	**More neurodivergent or trained/caring professionals within the justice system** (e.g., specialised staff within the justice system; employing autistic/neurodivergent correctional officers)	*"Employment of neurodivergent individuals at all levels."* (ID 501) *"Actually employ people who understand and care in all the systems that try and prevent a person from being engaged in the justice system. I had a client in his 20's who was functioning at 2 year old level and could not speak so would enter shops and take items – and was charged for shop lifting and then thrown in Jail – he was mentally 2 years old. Everyone feared him because he was 7 foot tall."* (ID 853)	6%	6%	6%	9%
8	**Develop a means to better identify that a person is autistic** (e.g., through assessment and diagnostic services within the justice system and more broadly; identification cards, etc.) (e.g., diagnostic assessments should be available for those in the justice system)	*"On licence or identification stating [autistic] with need for quiet tone, gentle lights and extra processing or something equivalent."* (ID 596) *"Clinical assessment for all individuals at risk of a custodial sentence (not a court clinician but an experienced consultant with appropriate qualifications)."* (ID 426)	5%	4%	7%	7%

Note. *all other groups that have not been identified separately

3.6.1.4 Factors that are working well, or have worked well, for autistic people in relation to the justice system

A total of 56 respondents opted to answer this question on the justice system. This included 34 autistic people and 42 family members or carers of autistic people. From these responses, the factors that are reported to be working well, or have worked well, for autistic people in relation to the justice system were coded into five categories, which fall under four broad areas:

- Nothing is working well/has worked well
- When there is autism-specific knowledge, awareness, and understanding of professionals in the justice system gained via training and first-hand knowledge and experience
- When there is advocacy, access to supports/funding, and accommodations when engaging with the justice system
- “Don’t know”.

Table 38 ranks the five most commonly reported factors that respondents reported to be working well, or have worked well, for autistic people in relation to the justice system. The data are ranked from most frequently reported to least frequently reported factors that are working well across all respondents. The right-hand columns report what proportion of specific respondent groups reported this as a factor that is working, or has worked well.

Importantly, these data show that approximately:

1 in 2 respondents did not feel that anything is working/has worked to support autistic people within the justice system.

1 in 4 stated that when there is autism-specific knowledge, awareness, and understanding of professionals (gained via training and first-hand knowledge and experience), the justice system works well..

Table 38: 5 most frequently reported factors that are working well, or have worked well, in relation to autistic people accessing the justice system

Rank	What is working well, or has worked well, in relation to autistic people accessing the justice system and sample quotes from responses	Direct insight	% who stated this as a problem			
			All respondents *N* = 56	Autistic people n = 34	Family member/ caregiver of autistic person n = 42	Other respondent groups* n = 56
1	**Nothing is working well/has worked well**	*"Nothing is working because normally if you get too emotional you are put on a Psych hold and therefore are demeaned and ignored over your true innocence."* (ID 793) *"Nothing from what I hear. Jailing a 19 year old autistic boy for 9 months is NOT the solution to him having aggression."* (ID 860)	45%	53%	41%	45%
2	**When there is autism-specific knowledge, awareness, and understanding of professionals in the justice system gained via training and first-hand knowledge and experience** (e.g., when front line workers understand autistic behaviours; when court social workers are aware of barriers autistic people face)	*"I've found police officers who have autistic children/ family are able to identify early and be supportive rather than authoritarian."* (ID 381) *"Most police in the field we have come across are very understanding and knowledgeable."* (ID 587)	23%	18%	31%	23%
3	**When there is access to support people/advocacy** (e.g., the use of intermediaries for witnesses; access to disability advocates)	*"Autistic people can generally have support persons present with police interviews and when giving evidence."* (ID 866) *"Court [liaison] officers who understand autism are gold."* (ID 1167)	20%	21%	19%	20%
4	**When there is access to other supports within the justice system** (e.g., links between the justice system and the NDIS; support animals/therapy animals in court)	*"[When] paperwork is helped with."* (ID 858) *"Separate listings in court to the regular listings (for example the ARC [Assessment and Referral Court] List in the Magistrate's Court in Victoria)."* (ID 1365)	16%	18%	17%	16%

Rank	What is working well, or has worked well, in relation to autistic people accessing the justice system and sample quotes from responses	Direct insight	% who stated this as a problem			
			All respon-dents *N* = 56	Autistic people n = 34	Family member/ caregiver of autistic person n = 42	Other respondent groups* n = 56
5	**"Don't know"**	*"I don't know but minorities are at a disadvantage."* (ID 196) *"Don't know, sorry."* (ID 1269)	11%	9%	10%	11%

Note. *all other groups that have not been identified separately

3.6.2 Umbrella review

An umbrella review is a form of research that brings together the findings of all existing reviews (systematic and scoping) that report on a specific topic. This umbrella review aimed to identify the systematic reviews relating to any aspect of the justice system for autistic individuals. This included legal, policing, judicial, and custodial services, with the autistic person being a victim, witness, or offender. The terms used for the searches and the number of articles identified, screened, and included are provided in Appendix I-1 and Appendix I-2. The final umbrella review consisted of 20 articles, none of which were written by Australian authors. Over half (*k* = 12) of the reviews were written in the last five years. The 20 reviews collectively report on 272 individual studies.

The information and findings from the included reviews are summarised in the subsections below. When reporting on the number of people or participants in the review, this will be represented as *n* = [number of participants]. When reporting on the number of reviews that considered a topic, this will be represented as *k* = [number of reviews].

3.6.2.1 Participants within included reviews

In total, the reviews included 705,833 participants, with sample size for individual studies ranging from 9 to 633,051 (*M* = 32,791.90; *SD* = 141,577.95). Of these 30,693 (4.35%) were reported to be autistic.

Only six systematic reviews provided information on the gender of autistic participants. The majority of the autistic participants in these six reviews were male (average percentage = 89.81%). Autistic participants, or the case studies reported, ranged in age from 5 to 74 years.

3.6.2.2 Quality of included reviews

The quality of the included systematic reviews was assessed using the JBI Critical Appraisal Tool for Systematic Reviews. This tool assesses the methodological quality of a systematic review. The maximum score is 33, which indicates a very high-quality systematic review. The average quality score for the 20 included systematic reviews was 25.15 (76.21%), with the quality score ranging from 17 to 32.

3.6.2.3 Topics of included reviews

The 20 reviews identified in the area of the justice system covered nine topics; some reviews discussed multiple topics. These were the prevalence and factors/characteristics associated with contact with the justice system (generic *k* = 4 reviews; as offenders of specific offences *k* = 12 reviews); autistic and autism community's experiences with, and perceptions of, the police (*k* = 2); professionals working in justice system: autism training, knowledge, and experience (*k* = 5); interviewing autistic individuals (*k* = 2); court experiences and outcomes (*k* = 2); custody and confinement experiences (*k* = 3); treatments for specific offence types (*k* = 3); and victimisation (*k* = 4). The key findings for each topic are presented in Table 39.

3.6.2.4 Research gaps

After reading the 20 reviews, the research team identified a number of key research gaps. These are combined with relevant research gaps noted within the reviews and summarised into Table 39.

Overall, there is a dearth of research which considers autistic people's experiences of interacting with the justice system as a victim or witness. Such work is critical given that victims and witnesses have to experience many of the same justice system processes or environments as offenders (e.g., being interviewed, the courtroom). There is also a need for research to identify ways to make those environments more inclusive and supportive for autistic people.

Almost all of the research on autistic offenders is based on case studies and the significant majority of those case studies are male, meaning that little is known about non-male autistic offenders. Many of the studies, including intervention studies, use approaches designed for non-autistic people, meaning that little is known about autism-specific pathways into or out of crime, or factors which may put autistic people at increased likelihood of specific crimes.

There was a consistent finding that members of the justice system lack of knowledge of autism, how autistic people may present in justice settings, and ways to support autistic people in justice settings. This highlights the need for research to address this issue through co-developed and co-delivered training, the impact of which should be assessed through subjective and objective methods.

Table 39: Umbrella review findings for justice

Topic	Number of reviews on topic; citations	Key findings	Key research gaps identified
Prevalence and factors/ characteristics associated with contact with justice system	*k* = 4 Collins et al. (2022) Cooper et al. (2022) King & Murphy (2014) Railey et al. (2021)	• Prevalence of autism in unbiased samples of offenders is 3%, slightly higher than that reported in adult community samples. However, some studies with a non-autistic control group suggest no difference in offending rate between autistic individuals and non-autistic individuals. None of these studies used Australian data. • A late diagnosis of autism, co-occurring intellectual disabilities and mental health challenges, conduct problems, and a history of family/childhood adversity are associated with an increased likelihood of offending in autistic individuals • Substance use and personality disorder, whilst lower in autistic offenders than in non-autistic offenders, are still associated with an increased risk of offending.	• Autistic people's perspectives on the pathways that led them into offending or being close to offending • High-quality, unbiased studies (with a well-matched control group) to provide an accurate prevalence rate of autism amongst offenders. Once this unbiased sample is identified, risk factors (including autism-related factors, environmental factors, and the role of mental health) for offending can be evaluated. • Prevalence and risk factor for offending across the lifespan • Studies which report on other genders, a broader ethnicity group, and those with varying cognitive ability levels are needed as almost all studies in autistic offenders are based on autistic white males without an intellectual disability • The factors that put autistic individuals at increased risk of being a victim of an offence, and therefore coming into contact with the justice system for a different reason.

Topic	Number of reviews on topic; citations	Key findings	Key research gaps identified
Prevalence and factors/ characteristics associated with specific offence types	*k* = 11 Allely et al. (2014) Allely (2018) Allely & Creaby-Attwood (2015) Allely & Dubin (2018) Bjorkly (2009) Cooper et al. (2022) Im (2015) King & Murphy (2014) Mercer & Allely (2020) Rutten et al. (2017) Schnitzer et al. (2020)	• Autistic people may be more likely than non-autistic people to commit offences against people, and less likely to commit offences against property or driving or drug offences. Some small empirical studies suggest there may be an elevated risk of arson but this requires further evaluation. • Many of the reviews relied heavily on case study reports. There were few empirical studies, and few with unbiased samples • Autism-related factors, such as social misunderstandings, differences with perspective taking, and special/deep interests are frequently identified as motivations for multiple offence types (sex offending, arson, stalking). Sensory elements are also discussed in relation to violence • If the contributing factors leading to offending differ for autistic people, then risk assessment tools designed for non-autistic people may not be accurate and treatments designed for non-autistic people may not be effective	• Autistic people's perspectives on the pathways that led them into a specific offence type • High-quality, unbiased studies (with a well-matched control group) to provide an accurate prevalence rate of autism amongst offenders convicted of specific offence types. Once this unbiased sample is identified, risk factors (including autism-related factors, environmental factors, and the role of mental health) for each offence type can be evaluated. Identifying prevalence and risk factors across the lifespan will help to identify stable and dynamic risk factors and avenues for early support or prevention • Development of reliable measures and tools. This includes measures of specific crime types as well as the factors (general and autism-specific) which may lead or, or contribute to, offending or re-offending
Autistic and autism community experiences with, and perceptions of, the police	*k* = 2 Cooper et al. (2022) Railey et al. (2021)	• American and Canadian studies suggest that approximately 1 in 5 autistic people (16-20%) will have had contact with the police within the last 12-18 months. Australia-specific data are not reported. • A series of studies, including an Australian study, indicate that almost two-thirds of the autistic or autism community who have contact with the justice system are "dissatisfied" with their experience • Negative experiences are generally related to unmet needs and a lack of knowledge and awareness of autism amongst the police. These negative experiences lead to distrust and fear, and a reluctance to go to the police in the future. • Parents of autistic children generally report that their autistic child's experience with the police was satisfactory, with some suggesting the police provided a calming effect.	• Australia-specific data of how often autistic people interact with the police or other members of the justice system officials and their experiences of these interactions. These interactions may be when they are victims, witnesses, or offenders. • Australia-specific data on how often an autistic person may have wanted to interact with the police (or other members of the justice system) and not done so • Autistic people (and their supporters') perspectives on how to make different parts of the justice system more autism inclusive. This includes procedures and physical spaces such as police stations, interview rooms, cells, court rooms and prisons. • Whether knowledge of autism within the justice system impacts the autistic person's experience or perception of the interaction.

Topic	Number of reviews on topic; citations	Key findings	Key research gaps identified
Professionals working in justice system: autism training, knowledge, and experience	*k* = 5 Cooper et al. (2022) Railey et al. (2020) Railey et al. (2021) Schnitzer et al. (2020) Sreckovic et al. (2022)	• Professionals within the justice system may have incorrect beliefs about autism, which may come from media coverage rather than from professional training. Professionals within the justice system who have a personal connection to autism have higher and more accurate knowledge of autism than those without a personal connection. • The majority of professionals within the justice system cannot identify the key characteristics of autism and do not feel equipped to work with autistic people. Most identify a need for training on autism. • Studies evaluating autism-specific training with American and Irish police used a range of methods, from a 13-minute video to multiple interactive sessions with live feedback, coaching, and debriefing. Less than half were co-developed and/or co-delivered with autistic people. No Australian studies on training were identified in the reviews. All the training resulted in increased autism knowledge and confidence. Whilst improving knowledge is positive, there is a need to ensure that this leads to action, as even professionals within the justice system who feel able to recognise the characteristics of autism report difficulty in knowing how best to support autistic individuals when accessing the justice system. • Staff training on autism should be a prerequisite to delivering treatments to reduce reoffending.	• Document current autism knowledge and training for professionals working within the Australian justice system • International comparisons of autism knowledge and training amongst professionals within the justice system; Love et al.'s (2023) Global Criminal Justice Survey enables this to occur • Co-development of autism-specific training for all professionals in the justice system, evaluated by objective methods (e.g., role-play, video observations) both immediately and 6 months post training. With the ongoing expansion of knowledge in this area, this training may need to be refreshed (e.g., every 2 years). • Co-development of training for professionals in the justice system which addresses intersectionality n autistic people (e.g., race, co-occurring conditions).
Interviewing autistic individuals (as witnesses, victims, or offenders)	*k* = 2 Cooper et al. (2022) Railey et al. (2021)	• Standard interviewing processes (using open-ended, non-leading questions) are ineffective for many autistic individuals • Adjustments, such as narrowing parameters in a non-leading manner and the use of intermediaries, can help improve the amount of information shared during interviews • Autistic children and adults are no more suggestable than non-autistic people.	• Training required for, and the efficacy of, intermediaries for autistic people • Given the increased risk of being a victim to specific crimes (noted above) – development of effective and acceptable interviewing practices for autistic people, evaluated by an independent research team

Topic	Number of reviews on topic; citations	Key findings	Key research gaps identified
Court experiences and outcomes	*k* = 2 Allely & Cooper (2017) Cooper et al. (2022)	• Autistic people report court experiences as "overwhelmingly negative" and, compared to matched controls, had more difficulty in understanding the processes and proceedings. Few accommodations made for communication or sensory needs • Informing judges and jurors that the person providing evidence is autistic improves their perception of the autistic individual and their credibility • Informing judges that a defendant is autistic influences their decision-making and sentencing, with therapy and supports being seen as more appropriate than prison for autistic offenders	• Autistic people (and their supporters') perspectives on what court supports are needed • Evaluation of the impact of reasonable court/trial modifications on autistic people's understanding of, and engagement with, court experiences • Co-development of processes for disclosing an autism diagnosis and methods to effectively explain this to jurors • Juror/judge perceptions of live, interactive testimonies from autistic people (previous studies have relied on video testimonies). This can be conducted in conjunction with evaluating the impact of training on autism or a person's disclosure of their autism diagnosis on judge/juror perceptions
Custody and confinement experiences	*k* = 3 Allely (2018b) Cooper et al. (2022) Railey et al. (2021)	• Prevalence of autistic individuals in confinement varies widely (2-17%) based on methodology • Confinement is accompanied by sensory and communication challenges for autistic individuals. These challenges are further exacerbated by the anxiety caused by the uncertainty and unpredictability of such settings • Relatively dated studies suggest a prevalence rate of autism of 2.4% within secure psychiatric hospitals in the UK, which was approximately three times higher than the rate in the community at the time those data were published • Legal terminology and jargon make the explanations of an individual's rights and entitlements "inaccessible" for many autistic individuals • The structure and routines of prison are appreciated by some autistic offenders. However, the majority of autistic offenders report challenges with the prison environment, and high levels of victimisation from other inmates. This leads to increased self-harm and to attempts to self-isolate	• Accurate prevalence of Australian autistic children, adolescents, and adults currently in confinement (e.g., prison, juvenile detention centre, or forensic hospital) and support provided to prevent negative outcomes during such time • Development and evaluation of accessible ways to explain rights and entitlements for autistic individuals and ways to assess that such information has been understood • The experiences of autistic people after release from prison; their access to mental and physical healthcare and supports to facilitate a safe and effective transition back into the community

Topic	Number of reviews on topic; citations	Key findings	Key research gaps identified
Treatments for specific offence types	*k* = 3 Cooper et al. (2022) Melvin et al. (2017) Schnitzer et al. (2020)	• Research to date is predominantly reporting on case studies or case series. The main focus has been on treatment for sex offending. • Whilst some treatment programs designed to reduce reoffending in non-autistic offenders are reported to offer social benefits for autistic offenders, they do not have sufficient quantitative evidence for reducing reoffending. Some qualitative reports exist on improvements • A lack of suitable treatments for autistic offenders • Adaptations made to therapy included simplification of concepts, making concepts more concrete, visual aids, social stories, and additional repetition of techniques and homework	• Development and high-quality evaluation of autism-specific treatments for specific offences, with long-term, objective data collection • The experiences of autistic people who have received treatment for their offences and how, if at all, it has supported them to prevent reoffending behaviour
Victimisation	*k* = 4 Collins et al. (2022) Cooper et al. (2022) Hellstrom (2019) Trundle et al. (2022)	• International data indicate that autistic people (predominantly children) are more likely to be victims of specific crimes, including sexual victimisation, abuse, assault, and robbery • A meta-analysis on victimisation (predominantly based on child data) estimates prevalence of 16% for child abuse and 40% for sexual victimisation. Only one Australian study contributed data to these prevalence rates. • A history of victimisation is one the most robust predictors of later offending in autistic individuals	• Prevalence of different forms of victimisation, revictimisation, and polyvictimisation in Australian autistic children and adults • Reporting rates of victimisation, support received, and perceived effectiveness of the support • The impact of victimisation in autistic people on mental health and well-being

Policy and guideline review

To capture a broad range of policies and guidelines at a national and/or state/territory-based level, a series of internet searches were conducted (see Appendix I-4 or more information). The policies and guidelines identified covered a range of sectors relevant to the justice system, including Australian Federal Police, Law Council of Australia, Australian Human Rights Commission, state/territory-level Attorney General, and Queensland Police Service. Information within the identified policies relevant to autistic individuals or people with disability is summarised in Table 40.

These policies and guidelines were all published or updated between 2000 and 2023, with 87% (k = 26) published or updated in the last 5 years (2018 to 2023). All 30 included policies provided some information relevant to individuals with disabilities; only five (17%) provided informed directly relevant to autistic individuals. The policies summarised in Table 40 were distributed across national and state/territory level: eight from a national level, three from Australian Capital Territory, three from New South Wales, three from Northern Territory, three from Queensland, five from South Australia, two from Tasmania, three from Victoria, and 0 from Western Australia. While additional policies were considered during this review (including those from Western Australia), only those that provided (a) information relevant to either autistic people or people with disability, or (b) additional unique information over and above that already summarised in Table 40, were included.

Where policies could not be found, it may indicate that autism-related policies or guidelines are not available for that sector of the profession, that they are accessible only for individuals working within the profession, or that they are difficult to access. The latter suggests that people working in, or interested in, this sector or profession may have difficulty accessing information that may assist in supporting autistic people.

3.6.2.5 Policy and guideline relevant to autistic people

The five documents that specifically discussed information pertinent to autistic individuals highlighted that within the justice system:

- There are differing definitions of cognitive impairment, yet within the documents, cognitive impairment is often written about as if it is similar to autism. Sometimes autism is conflated with cognitive impairment, potentially and incorrectly implying that all autistic individuals experience cognitive impairment.
- Autism diagnosis should be considered when interpreting behaviour in court.
- The physical environment (e.g., lights, sounds) should be considered to support accessibility. This relates to the sensory differences experienced by autistic people.
- A specialist court process (Assessment and Referral Court List) has been developed in Victoria to address the underlying factors that may have contributed to offending.

3.6.2.6 Policy and guideline relevant to people with disability

The 30 polices and/or guidelines that provided information pertinent to individuals with disabilities revealed that, within the justice system:

- Accessibility needs to be considered throughout the justice system to overcome barriers within the system. This includes:
    - Communication methods being tailored to support the needs of people with disabilities, including Easy English options (e.g., simple words and pictures). This is relevant throughout the justice system, including during the moment of arrest and within the court system
    - Creating a physical environment that is responsive to the needs of people with disability
    - Modifications being made where reasonable to support the participation of people with disability in the justice system. This aligns with policies stating that people with disability should not experience discrimination based on the grounds of disability and should be treated with dignity during the justice process.
- A person's cognitive impairment or disability should be considered when:
    - Making decisions regarding the fitness of a person to stand trial or be a witness. Where possible, accommodations should be made to support the individual (e.g., providing evidence in a closed court; having an advocate stand in their place; having a support person)
    - Determining a sentence for an offence
    - Identifying whether special care and treatment is required within or outside of the facility.
- People with disability are overrepresented in the criminal justice system in Australia. Reforms are required to support better access to legal systems for this population. Additionally, the underlying factors that may be associated with this overrepresentation need to be considered. These factors include higher rates of poverty and unemployment and lower educational outcomes for this population
- Individuals with disabilities should be consulted in discussions about the law, with ongoing input into its the design, implementation, and evaluation
- Inclusive practice should be implemented, including when considering the setting in which people with disability are detained. This should also be recovery oriented, acknowledging individual differences in the meaning of recovery or rehabilitation.

Table 40: Policy and guideline review findings for justice

Organisation level	Organisation name	Policy name	Policy date	Reference to autism	Reference to disability	Relevant information
National	Australian Federal Police	Australian Federal Police Act 1979	2021	✕	✓	• Where a protective service officer who arrests a person for an offence believes or has reasonable grounds for believing that the person is unable, by reason of inadequate knowledge of the English language or any physical or mental disability, to understand the substance of the offence for which the person is arrested, the protective service officer must, as soon as practicable, take all reasonable steps to ensure that the person is provided with an explanation of the substance of the offence that the person is able to understand.
National	Australian Law Reform Commission	How we Talk with People with Disability	n/a	✕	✓	• Communicate in Easy English (i.e., simple words and pictures) • Include people with disabilities in discussions regarding law.
National	Attorney-General Department	Criminal Code Act 1995	2022	✕	✓	• If the police officer who is detaining a person under a preventative detention order has reasonable grounds to believe that the person is unable, because of inadequate knowledge of the English language or a disability, to communicate with reasonable fluency in that language: – The police officer has an obligation under subsection 105.31(3) to arrange for the assistance of an interpreter in informing the person about: (1) the effect of the order or any extension, or further extension, of the order; and (2) the person's rights in relation to the order – The police officer has an obligation under subsection 105.37(3A) to give the person reasonable assistance to: (1) choose a lawyer to act for the person in relation to the order; and (2) contact the lawyer.

Organisation level	Organisation name	Policy name	Policy date	Reference to autism	Reference to disability	Relevant information
National	Law, Crime and Community Safety Council	National Statement of Principles Relating to Persons Unfit to Plead or Not Guilty by Reason of Cognitive or Mental Health Impairment	2015	×	✓	• Policies, procedures and services should aim to recognise and reflect the distinction and interaction between the concepts of cognitive impairment and mental health impairment • The concepts of cognitive impairment and mental health impairment should be defined broadly, focusing in general on the effect of the impairment rather than on the inclusion or exclusion of particular conditions • Decision making should be guided by the least restriction of the rights of a person with cognitive or mental health impairment taking into account the risk of harm they may pose to themselves, victims or others • The setting in which people are detained should aim to be inclusive and recovery-orientated, acknowledging that there will be individual differences in the meaning of recovery or habilitation and what it may entail • Information about the rights of persons detained under orders and how they may be exercised should be readily available to relevant persons and their families, guardians and carers in a format and mode by which this information may be understood • People who are detained following an order are entitled to receive health care (including mental health care) and support at an equivalent level to that available to people in the community • Duty of care should be a primary consideration when treating young people with cognitive or mental health impairment. Young people should be provided with care, protection and all necessary individual assistance in view of their age, sex and personality and, if detained, young people should be separated from adults.

Organisation level	Organisation name	Policy name	Policy date	Reference to autism	Reference to disability	Relevant information
National	Law Council of Australia: Department of Social Services	National Disability Strategy	2020	×	✓	• Reflect Australia's obligations under the Convention on the Rights of Persons with Disabilities (CRPD) in protecting, promoting and fulfilling the human rights of people with disability • In terms of rights protection, justice and legislation, there are strong examples of initiatives to support people with disability to participate in the justice system on an equal basis with others. Where they have not already done so, Commonwealth, state and territory governments should implement Disability Justice Plans to champion cultural change and practical improvements across the justice system • Within the criminal justice system, people with disability face worryingly disproportionate outcomes, as well as many systemic and structural barriers to accessing justice. Legislative reforms, better access to legal assistance services, as well as preventative and rehabilitative critical support services to address the underlying factors which cause many people with disability to become embroiled in the system in the first place, are all needed to overcome these barriers • Solutions include a review of current laws concerning unfitness to plead, as well as evidence laws to allow and prompt a more flexible approach to adducing evidence from witnesses with complex communication needs, the expansion of communication intermediary schemes, the adoption of a National Justice Interpreter Scheme and targeted measures to train all parts of the criminal justice sector – including the police, judiciary, legal practitioners and corrections - on better identifying and responding to the needs of people with disability • Enhance the accessibility of Australia's anti-discrimination framework, a shift towards formal recognition of supported decision-making, nationally consistent laws dealing with individual decision-makers, and removing barriers that prevent people with disability from participating in jury service • Provide support for a strong disability-inclusive research agenda. The Law Council is concerned by the dearth of good data and research that is needed to improve mainstream programs and policies which affect people with disability • Involve and engage people with disability during consultations. It is fundamental that people with lived experience of disability are involved on an ongoing basis with its design, implementation and evaluation. Intersectional perspectives are critical in this regard.

Organisation level	Organisation name	Policy name	Policy date	Reference to autism	Reference to disability	Relevant information
National	Australian Government: Australian Institute of Health and Welfare	People with Disability in Australia	2020	✕	✓	• This is a large and detailed document, so the critical parts have been summarised as: people with disability may experience higher rates of violence, abuse and neglect than people without disability. Some may also face barriers in asserting their rights before the law. Exploring the extent of violence experienced or perpetrated by people with disability, as well as their interactions with the justice system and the quality and safety of the supports they receive, can provide information to improve outcomes for this vulnerable group.
National	Australian Human Rights Commission	Equal Before the Law: Towards disability justice strategies	2014	✕	✓	• Disability Justice Strategy should focus on: (1) Safety of people with disabilities and freedom from violence, (2) Effective access to justice for people with disabilities, (3) Non-discrimination, (4) Respect for inherent dignity and individual autonomy including the freedom to make one's own decisions, (5) Full and effective participation and inclusion in the community • These outcomes reflect the understanding that people with disabilities: (1) Have the right to be heard and informed, (2) Should feel safe and be free from violence so that they can live in safety and with dignity, (3) Should be able to access the support, services, and programs they need to prevent disadvantage and address a range of health and social risk factors, (4) are able to easily identify and access appropriate high quality services if they experience violence, or feel they are unsafe and at risk of experiencing violence, (5) are treated with dignity when they begin or defend criminal matters, or participate in criminal justice processes, and the legal system provides the modifications, supports and aids needed to participate, (6) when lawfully deprived of their liberty are treated humanely and provided with supports, adjustments and aids needed to participate in prison life and transition successfully to the community • Factors included appropriate communication, early intervention and diversion, increased service capacity, effective training, enhanced accountability and monitoring, and better policy and frameworks are also considered.

Organisation level	Organisation name	Policy name	Policy date	Reference to autism	Reference to disability	Relevant information
National	Commonwealth of Australia: Department of Social Services	Australia's Disability Strategy 2021-2031	2021	×	✓	• Effective access to justice for people with disability requires consideration of individual needs. Without this there can be no equitable or equal participation. This requires appropriate strategies, including aids, equipment, and accessible legal information and advice to facilitate equal and effective participation in all legal proceedings. In addition, greater awareness of disability is needed among some parts of the judiciary, legal professionals and court staff • People with disability who have complex needs, multiple impairments and/or multiple and intersecting forms of disadvantage, face even greater obstacles within the justice system compared to other people with disability and people without disability. People with disability in the criminal justice system are at a heightened risk of violence, abuse, neglect and exploitation. Reducing the over-representation of people with disability across the criminal justice systems of Australia and other systems of detention requires appropriate strategies, including adoption of diversionary approaches and transition to community supports.
State	New South Wales Parliamentary Council	Crimes (Administration of Sentences) Regulation 2014	2022	×	✓	• In the case of an inmate who has a disability, a strategy to minimise any disadvantage suffered by the inmate because of the disability, including in relation to the inmate's suitability to carry out work.
State	New South Wales Attorney General	Evidence Act 1995 No 25	2022	×	✓	• Without limiting the matters that the court may take into account in deciding whether to disallow the question or give such a direction, it is to take into account the extent to which the witness's age, or any mental, intellectual or physical disability to which the witness is subject, may affect the witness's answers.
State	New South Wales Attorney General	Crimes Act 1900 No 40	2023	✓	✓	• A cognitive impairment may arise from any of the following conditions but may also arise for other reasons: (a) intellectual disability, (f) autism.
Territory	Australian Capital Territory	Juries Act 1967	2018	×	✓	• If a juror has a mental or physical disability that may impact their ability to properly discharge the duties of a juror, the judge must consider if support that would enable the person to properly discharge the duties of a juror can reasonably be given. If satisfied, the judge must make a direction that the support be given.

Organisation level	Organisation name	Policy name	Policy date	Reference to autism	Reference to disability	Relevant information
Territory	Australian Capital Territory, Attorney General	Evidence (miscellaneous provisions) act 1991	2022	×	✓	• A witness with a disability may have a support person and given evidence in closed court.
Territory	Australian Capital Territory, Law Council of Australia	The Criminal Justice System – Issues Paper: Royal commission into violence, abuse, neglect and exploitation of people with disability	2020	✓	✓	• This document contains a lot of relevant information. The most pertinent of which is summarised as: • Physical accessibility includes making a building physically accessible for people with impaired mobility as well as creating a physical environment that is responsive to the needs of people with disability generally. For example, fluorescent lighting or extraneous noise can be distracting for people with mental health conditions, and bright colours can affect the mood and behaviour of people on the autism spectrum. The formal design and structure of the courtroom can influence people's experience of justice • The Assessment and Referral Court List (ARC) is a specialist court list within the Melbourne Magistrates' Court that is designed to meet the needs of accused persons who have or are likely to have a mental health condition, cognitive impairment, intellectual disability, ABI, autism and/or neurological impairment, including dementia. The ARC aims to address the underlying causes of offending behaviour in order to reduce the likelihood of reoffending and decrease the number of prisoners with mental impairment. It also aims to 'increase public confidence in the criminal justice system by improving court processes and increasing options available to courts in responding to accused persons with a mental impairment' • People with disability are over-represented across the criminal justice system in Australia. While not in themselves 'causes' of violence, abuse, neglect or exploitation of people with disability in the criminal justice system, important 'enablers' include higher rates of poverty and unemployment and lower educational outcomes, often stemming from systemic discrimination • A lack of disability awareness also means that there is insufficient broader policy planning and resourcing to ensure that the diverse needs of people with disability are anticipated and met within the criminal justice system, as evidenced, for example through a lack of disability-responsive rehabilitative prison services

Organisation level	Organisation name	Policy name	Policy date	Reference to autism	Reference to disability	Relevant information
						• Many people with disability who are offenders have a long history of undiagnosed or untreated impairment, poor health and/or trauma, with their behaviour misinterpreted as difficult or defiant. This leads to disproportionate interactions with police and ultimately, a 'criminalisation of disability' • Within the justice system, people with disability face many systemic and structural barriers to accessing justice. These include inaccessible information, formats and processes, physical inaccessibility, poor communication, inflexible court procedures, and an under-resourced legal assistance sector. Without efforts to overcome these barriers, the system will remain largely inaccessible for many people with disability and continue to produce unjust outcomes • The over-incarceration of First Nations persons with disability, including very high proportions of First Nations children and young people, is under-explored Commonwealth, state and territory governments should implement Disability Justice Plans to champion cultural change and practical improvements across the criminal justice system.
Territory	Northern Territory	Juries Act 1962	2022	×	✓	• A person with a disability who, as a result of that disability, is incapable of discharging the duties of a juror is exempt from service as a juror.
Territory	Northern Territory	Child Protection (Offender Reporting and Registration) Act 2004	2023	×	✓	• A court, in determining whether a person had a reasonable excuse for failing to comply with his or her reporting obligations, must have regard to the following matter: whether a person has a disability that affects his or her ability to understand or comply with those obligations • If a reportable offender attending in person is a child or has a disability that makes it impracticable for him or her to make a report, a parent, guardian, carer or other person nominated by the reportable offender who is accompanying the reportable offender may make the report on the reportable offender's behalf.
Territory	Northern Territory	Evidence Act 1939	2020	×	✓	• A vulnerable witness means a witness in proceedings: (a) who is a child; or (b) who has a cognitive impairment or an intellectual disability. The defendant is not entitled to cross-examine the witness directly unless the court grants leave. • The court cannot grant leave under subsection (2), if the witness is a child, or has a cognitive impairment or an intellectual disability.

Organisation level	Organisation name	Policy name	Policy date	Reference to autism	Reference to disability	Relevant information
State	Queensland Attorney General	Inspector of Detention Services Act 2022	2022	×	✓	• For a review relating to a detainee with a disability, it may be appropriate for the inspector to consult with a: (a) parent, legal guardian or close friend of the detainee; or (b) a representative from an advocacy services agency.
State	Queensland Police Service	Police Powers and Responsibilities Act 2000	2023	×	✓	• When determining whether a missing person is high risk, any disability of the person attributable to a cognitive, intellectual, neurological, physical or psychiatric impairment should be considered • An interpreter can be sought if a police officer reasonably suspects a relevant person is unable, because of an inadequate knowledge of the English language or a physical disability, to speak with reasonable fluency in English.
State	Queensland Children, Youth Justice, and Multicultural Affairs	Youth Justice Act 1992	2023	×	✓	• For a child with a disability—the disability and the child's need for services and supports in relation to the disability should be considered in making decisions about release and bail.
State	South Australia Attorney General	Criminal Procedure Act 1921	2023	✓	✓	• Cognitive impairment includes a developmental disability (for example, intellectual disability, Down Syndrome, cerebral palsy, or an autism).
State	South Australia Attorney General	Summary Offences Act 1953	2023	✓	✓	• When a person is disrespectful in court, it must be considered if the person has a cognitive impairment (including autism and intellectual disability).
State	South Australia Attorney General	Sentencing Act 2017	2022	✓	✓	• In determining a sentence for an offence, a court must take into account the personal circumstances and vulnerability of any victim of the offence, including disability • Court to be notified if suitable community placement not available due to defendant's physical or mental disability • Cognitive impairment includes autism.

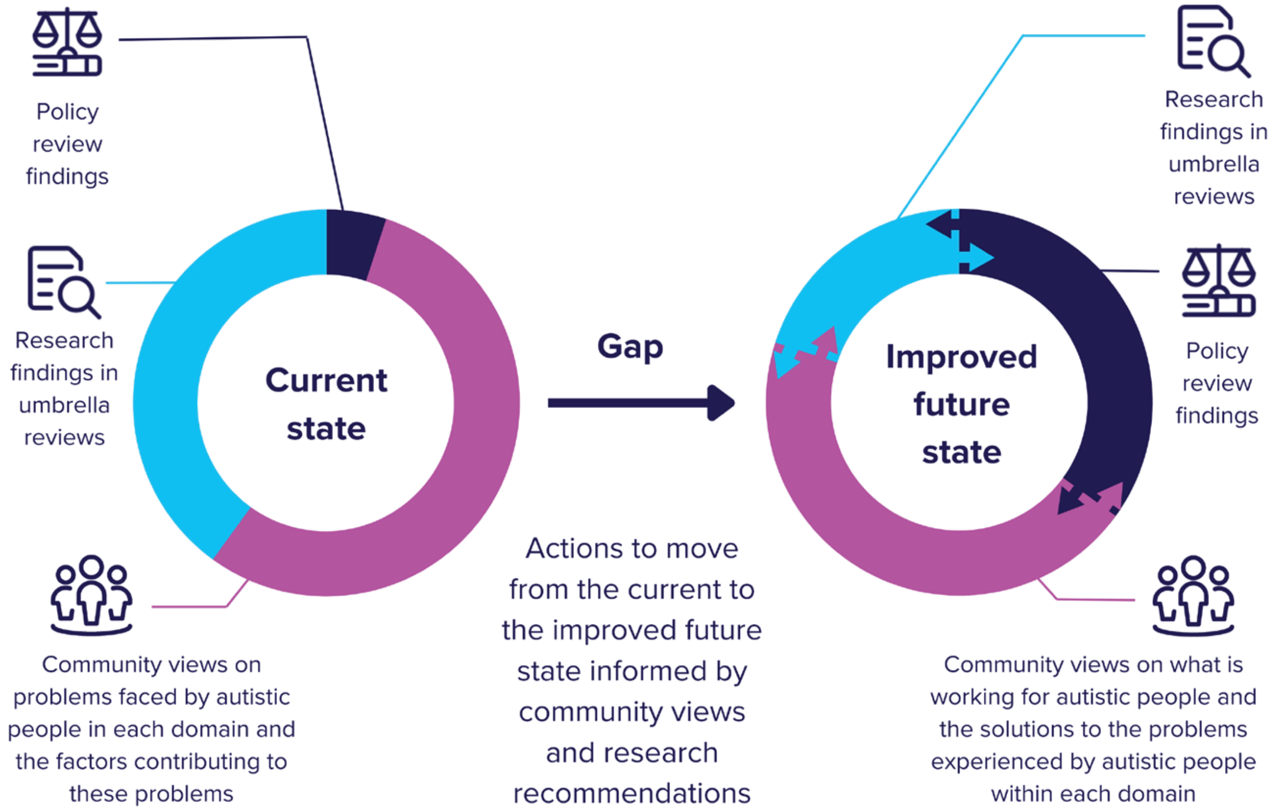
Organisation level	Organisation name	Policy name	Policy date	Reference to autism	Reference to disability	Relevant information
State	South Australia Police, Emergency Services and Correctional Services	Correctional Services Act 1982	2022	✕	✓	• Facilities and programs developed for the care, rehabilitation, imprisonment, training, therapeutic treatment or other treatment of prisoners, probationers and parolees should (1) be evidence-based; and (2) be individually designed as much as reasonably practicable— to take account of the prisoner, probationer or parolee's age, gender, gender identity, sexuality or sexual identity, cultural identity, developmental and cognitive capacity, ability or disability, and any special needs.
State	South Australia Police, Emergency Services and Correctional Services	International Transfer of Prisoners (South Australia) Act 1998	2000	✕	✓	• Mental impairment includes senility, intellectual disability, mental illness, brain damage and severe personality disorder. Mentally impaired prisoner means: (a) a person serving a sentence of imprisonment on the acquittal of the person for an offence on the ground of mental impairment; or (b) a person serving a sentence of imprisonment because the person has been found mentally unfit to stand trial.
State	Tasmania Chief Parliamentary Counsel	Corrections Act 1997	2021	✕	✓	• Every prisoner and detainee has the following rights: if the prisoner has an intellectually disability or mentally health challenge, the right to have reasonable access within the prison or, with the Director's approval, outside the prison to such special care and treatment as a medical officer considers necessary or desirable in the circumstances. The Director may direct that a prisoner or detainee who has a disability be removed from a prison, or a hospital or institution to which he or she has been removed under section 36, to a secure mental health unit.
State	Tasmania Chief Parliamentary Counsel	Anti-Discrimination Act 1998	2021	✕	✓	• A person must not discriminate against another person on the ground of disability.
State	Victoria Chief Parliamentary Counsel	Sex Offenders Registration Act 2004	2022	✕	✓	• If a registrable offender attending in person has a disability that renders it impossible or impracticable for him or her to make a report, any parent, guardian, carer or other person nominated by the registrable offender who is accompanying the registrable offender— may make the report on the registrable offender's behalf.

Organisation level	Organisation name	Policy name	Policy date	Reference to autism	Reference to disability	Relevant information
State	Victoria Chief Parliamentary Counsel	Corrections Regulations 2019	2019	×	✓	• In determining the placement of a prisoner, varying the placement of a prisoner or developing a sentence plan for a prisoner, a sentence management panel or the Secretary may consider whether the prisoner has any physical limitations or a disability.
State	Victoria Chief Parliamentary Counsel	Serious Offenders Act 2018	2018	×	✓	• If the offender has an intellectual disability or mental health problem, the right to have reasonable access within the facility or, with the approval of the Commissioner, outside the facility to any special care and treatment that is necessary or desirable in the circumstances.

3.6.3 Community views, research evidence, and policy/guideline alignment and gap analysis

As well as the research gaps identified as part of the research landscape mapping, the gap analysis (see Figure 7 for process) allows comparison of the *current state* (predominantly based upon the community views analysis but also some findings of the umbrella review and policy review) to an *improved future state* (based upon community views around what is working well, policy review, and some umbrella review findings).

Figure 7: Gap analysis: Current to improved future state



The gap analysis work for the justice system section highlighted the following elements that need to be addressed in order to reduce the problems experienced by autistic people in relation to the justice system:

3.6.3.1 There is a need to improve the level of autism knowledge and understanding of professionals working in the justice system

Current state

The **community** views survey highlighted the level of autism knowledge, awareness, and understanding of professionals in the justice system as the most common problem experienced by autistic people within the justice system. It also highlighted that there are problems with the characteristics of autism and/or autistic behaviour (e.g., meltdowns or differences in eye contact) being misinterpreted or treated as a criminal issue.

The **research** landscape mapping results align with the community views. The research landscape mapping highlighted that although autistic people are more likely than non-autistic people to come into contact with the justice system, there is a consistent lack of knowledge of autism amongst professionals within the justice system. While the systematic reviews included in the research landscape mapping described some evaluations of autism-specific training for police, none of these took place in Australia. Moreover, there were no studies of training of broader professionals (e.g., lawyers, judges, prison staff) within the justice system within the reviews to date.

Improved future state

The **community** views survey highlighted that the justice system works well for autistic people when there is autism-specific knowledge, awareness, and understanding of professionals in the justice system gained via training and first-hand knowledge and experience. Aligning with this, the most frequently suggested solution to the problems autistic people face within the justice system (within the community views survey) was increasing the autism knowledge of professionals within the justice system.

The Australian Human Rights Commission (2014) and the Commonwealth's "Australia's Disability Strategy" (2021) document in the **policy** review identify the need for effective training on disability for justice system professionals. However, none of the other policies reviewed suggested or mandated autism training for professionals in the justice system.

Steps that can be taken to move from the current to the improved future state include:

- Co-development (i.e., developed collaboratively with autistic people) and co-delivery (i.e., delivered collaboratively with autistic people) of evidence-based autism-specific training that is relevant and accessible to professionals in every aspect of the justice system. The effectiveness of this training could be supported by relevant federal and state policymakers suggesting or mandating completion of such training within policy.
- Co-development and co-delivery of specialised training for professionals whose role would benefit from specific knowledge of autism (e.g., police officers working directly with general public; prison officers supporting autistic inmates).

3.6.3.2 There is a need to find a way to identify autism and co-occurring conditions in autistic people accessing the justice system

Current state

The **community** views survey highlighted that undiagnosed autism and/or undiagnosed co-occurring conditions is an issue that autistic people face in relation to the justice system. A lack of access to diagnosis was highlighted as a *cause* of the problems faced by autistic people in relation to the justice system (i.e., lack of a pathway to receiving a diagnosis). Identifying that a person is autistic or that they have a co-occurring condition would also help to reduce another issue raised in the community views survey; that is, the characteristics of autism and/or autistic behaviour can be misinterpreted or treated as a criminal issue.

The **research** landscape mapping showed that professionals in the justice system cannot identify the key characteristics of autism. Importantly, however, it also showed that if judges and jurors are informed that a person is autistic, it improves the judge/juror perception of the autistic person which influences their decision-making towards therapy and supports. Given that professionals in the justice system may experience challenges in identifying autism characteristics, it is likely that for some (potentially undiagnosed) autistic people in court, autism is not recognised and therefore not considered when interpreting their behaviour.

Improved future state

The **community** views highlighted that one way to reduce the issues that autistic people face with the justice system is to incorporate ways to identify that a person is autistic, with some specific recommendations for diagnostic services and others recommending ID cards. Multiple **policies** specify specific rights for individuals with a disability (which, in terms of policy, would include autism), which relies on a diagnosis to have been previously made and disclosed.

Steps that can be taken to move from the current to the improved future state include:

- Collaboration between justice and health systems to provide pathways to autism assessments and diagnosis, ensuring equitable access to the justice system
- Co-development of clear pathways for autistic people to disclose their diagnosis of autism, taking into consideration potential fears of stigmatisation and discrimination based upon diagnosis. Some community recommendations included autism identification cards which are used by some police services in other countries (npaa.org.uk/alert-card-schemes/)
- Gain community and justice system professional views on consistent screening for a range of neurodivergent conditions for those entering the justice system. This would not be with the aim of diagnosing, but with the aim of: (a) identifying those who may benefit from referral on for diagnosis, and (b) identifying those who may benefit from supports or accommodations (discussed below).

3.6.3.3 There is a need to make justice systems settings more accessible and inclusive for autistic people

Current state

The **community** views survey identified that the sensory and physical settings of justice systems are a significant problem for autistic people trying to access the justice system. The community views survey highlighted that this can result in autistic people being unable to think, process information, or communicate within these settings. This was also highlighted within the **research** landscape mapping which reported that courts, custody, confinement, and interviewing settings pose multiple sensory challenges for autistic people.

Improved future state

The **policy** review includes a statement by the Law, Crime and Community Safety Council that settings in which people are detained should aim to be “inclusive”; the Australian Human Rights Commission document also highlights how the legal system should provide modifications and supports to enable participation in the justice system.

Steps that can be taken to move from the current to the improved future state include:

- Given the lack of knowledge and identification of autism in the justice system (discussed above), the initial focus would be to proactively make settings within the justice system inclusive for autistic people (rather than waiting for people to disclose their diagnosis, or for someone to identify that a person is autistic before making adjustments to the environment). Participative walkthroughs (like the work of Holloway et al. (2020): sciencedirect.com/science/article/pii/S0891422219302124) and environmental audits of each justice system setting (e.g., interview room, custody, court room) can provide initial feedback on the sensory elements of these settings. They can also recommend simple, low-cost, and easily implementable changes that can increase the inclusivity of the setting
- Co-development of recommendations for newly built or refurbished autism-inclusive justice system settings
- Co-development of the physical/sensory aspects required for accreditation of autism-inclusive justice settings, see autism.org.uk/advice-and-guidance/professional-practice/accreditation-prison. Accreditation could reflect that the organisation is committed to supporting autism knowledge within their establishment(s) and that the environment is designed to be supportive of autistic people and their sensory differences.

3.6.3.4 There is a need to provide effective supports and accommodations for autistic people to ensure equitable access to the justice system

Current state

The **community** views survey highlighted that supports and accommodations were often not offered to autistic people, and that autistic people's communication, language, and communication styles or preferences were not accommodated. There are many potential reasons for this, including a lack of autism knowledge, a lack of funding, resource- and time-constraints of those working in the justice system, or the justice system being based on neurotypical norms and expectations. There was limited **research** identified in the umbrella reviews that looked at which supports or accommodations may be effective. That which has been conducted focused on interviewing practices, yet there is a clear need for adjustments beyond interviewing practices to better support autistic people across the justice system.

Improved future state

The **community** views survey identified that the justice system works well for autistic people when there is access to supports. It further identified that to reduce the problems experienced by autistic people in relation to the justice system, there needs to be increased funding and access to supports, an individualised approach to accommodations, and increased input into the justice system from neurodivergent people. This could be through training or by increasing the number of neurodivergent people working in the justice system.

Multiple policies within the **policy** review emphasise the need to provide person-centred and evidence-based supports to people entering the justice system. For example, Australia's Disability Strategy (2021) states, "Effective access to justice for people with disability requires consideration of individual needs. Without this there can be no equitable or equal participation". Other policies also highlight that police and other professionals in the justice system need to ensure that any potential offender understands the offence of which they are being accused. However, sources for professionals in the justice system, which provide recommendations on the provision of supports, rarely mention autism. For example, the Supreme Court of Queensland's "Equal Treatment Benchbook" contains only one mention of the word autism, and that is within a statement encouraging judges to emphasise the person rather than the disability/diagnosis.

Steps that can be taken to move from the current to the improved future state include:

- Co-development of evidence-based supports and accommodations for supporting autistic people in different aspects of the justice system. Once these are evidence supported, there needs to be a pathway to dissemination so that such supports and accommodations are proactively available and offered to autistic people in every justice system setting.
- Co-development of resources and supports for autistic people to enhance their understanding of the legal system, and evaluation of the effectiveness of these resources and supports. Dependent upon community views, this may include supporting autistic people to proactively identify (either independently or with support) the accommodations or supports they may need should they be required to access the justice system.
- Some justice systems (including those in other countries) provide intermediaries or support individuals who are trained and knowledgeable about the supports or accommodations to which each autistic person is entitled. The Law Council's National Disability Strategy notes the adoption of the National Justice Interpreter Scheme. There is a need for Australian research into the use of intermediaries, interpreters, and/or support people and their effectiveness in supporting autistic people in order to inform the usefulness of each option as a potential support or accommodation.

3.6.3.5 There is a need to ensure that autistic people feel safe when accessing the justice system

Current state

The **community** views survey revealed that almost one in four autistic adults highlighted feeling scared of, dismissed by, or experiencing discrimination by justice system professionals as a problem for autistic people accessing the justice system. One in 10 autistic adults also reported discrimination and ableism as an issue which causes problems for autistic people within the justice system. The **research** landscape mapping identified that the distrust and fear of the police experienced by some autistic people leads to them feeling reluctant to go to the police even if they are a victim of a crime.

Improved future state

The Australian Law Council website states that "all Australians have a fundamental right to access to legal advice and services, regardless of their means, and considers that the justice system becomes meaningless if there are barriers that prevent people from enforcing their rights." This is echoed in **policies** reviewed, including the Australian Human Rights Commission Disability Justice Strategy (2014) which specifically states that there should be a focus on effective access to justice for people with disabilities.

Steps that can be taken to move from the current to the improved future state include:

- Further consultation with the autistic community as to how to maintain, or rebuild, trust between autistic people and those in the justice system.
- Co-development (with the autistic and autism communities) of alternative or autism-specific pathways and support for autistic victims and/or witnesses to feel safe and supported to report crimes and provide testimonies.
- Training (noted above) to address ableism and discrimination of autistic people.

3.6.3.6 There is a need to understand more about why autistic people come into contact with the justice system more often as victims, offenders, and/or witnesses

Current state

One in 10 people in the **community** views survey highlighted the increased risk of autistic people coming into contact with the justice system (e.g., through poor judgement, manipulation, or coercion) as an issue. The **research** landscape mapping verifies this; autistic people are more likely to come into contact with the justice system and the case study reports suggest some specific characteristics associated with autism (e.g., social misunderstandings, differences with perspective taking, and special/deep interests) that may increase the likelihood of this occurring. Many autistic people's interactions with the justice system are as victims and witnesses, and in contrast to the research (which focuses on autistic people as the offender), many of the comments within the community views survey focussed on autistic people as the victim of crime. For autistic people who come into contact as offenders, there are specific offence types which they are more likely than non-autistic people to commit. However, the majority of this research is based on non-Australian data and almost all on case-studies, which limits the generalisability of the findings.

Improved future state

Described in the **policy** review, the Australian Human Rights Commission's "Equal Before the Law: Towards Disability Justice Strategies" document states that every person with a disability should feel safe and be free from violence so that they can live in safety and with dignity. However, the research shows that autistic people are more likely to be victimised than non-autistic people. Policies also state that a person's diagnosis should be considered when identifying supports or interventions. However, there are no autism-specific strategies for offending and the research shows that strategies designed to prevent reoffending in non-autistic people are not appropriate or helpful for autistic offenders.

Steps that can be taken to move from the current to the improved future state include:

- Australian-specific data on how often autistic people interact with the police and the nature of their interactions. This would also be useful to inform the training described above
- At present, the research predominantly focuses upon autistic people as offenders but many of the problems raised in the community survey focussed upon autistic people who are victims and/or witnesses. This highlights the need to: (a) identify how and why autistic people are victimised, (b) identify ways to make autistic people safe and supported, and (c) ensure the research documents experiences and needs of autistic people accessing the justice system

as non-offenders. This may lead to the development of resources for autistic people and/or resources to promote community awareness and acceptance of autism and diversity

- Development and evaluation of autism-specific or autism-relevant models of offending which can then be used to develop supports or treatments tailored for autistic people who commit specific offence types.

3.6.3.7 There is a need to know more about diversionary pathways, how often they are used, and whether they provide the right support for autistic people

Current state

Although not discussed in the research specifically, alternative pathways for autistic people through the justice system are provided via The Victorian Assessment and Referral Court List, South Australia's Treatment Intervention Court (previously the Magistrates Court Diversion Program), Tasmania's Diversion List, and Western Australia's Intellectual Disability Diversion Program. However, little is known about their use or effectiveness.

Improved future state

Evidence-supported, effective, and accessible diagnostic-considerate court pathways and diversionary methods are needed across Australia.

Steps that can be taken to move from the current to the improved future state include:

- Use existing data to evaluate how many autistic people were referred to the courts listed above and diversionary methods, and evaluate experiences and outcomes of autistic people compared to those who have gone through the standard court process
- Document the experiences of autistic people who have been through these courts, including noting accommodations received and the impact that these accommodations had on the justice process.

3.7 Mental health services

3.7.1 The "1,000 Insights" community views survey

A total of 539 respondents answered at least one of the questions on the mental health service. This included 250 autistic people, 327 family members or carers of autistic people, 75 mental health professionals, and 130 medical or allied health professionals. The 10 most frequently reported responses (where applicable) are reported within this section.

The tables for each question describe the response categories (with example participant responses) in order from the most frequently reported to the least frequently reported. For each category, percentages are provided to indicate the proportion of a respondent group whose response reflected the specific category. These groups are: (a) the entire sample (i.e., everyone), (b) autistic people, (c) family members/caregivers of autistic people, (d) mental health professionals, (e) medical or allied health professionals, and (f) all respondents who are not represented in one of these groups.

3.7.1.1 Problems experienced by autistic people when using, or trying to access, mental health services

A total of 539 respondents opted to answer this question on using, or trying to access, mental health services. This included 250 autistic people and 327 family members or carers of autistic people. The problems experienced were coded into 20 categories, which fall under the following eight broad areas:

- Challenges with obtaining a correct diagnosis
- Insufficient access to mental health professionals
- Lack of, or poor quality, autism knowledge and therapeutic skills held by mental health professionals
- Challenges with excessive cost or accessing funds
- Practices and strategies are not tailored to, or supportive of, autistic people
- Professionals may make assumptions or have preconceived ideas of autism (including holding a deficit-based view)
- Lack of autism training for people working in the mental health field
- Lack of communication between sectors/professionals leading to autistic people falling between the cracks and/or frustration (e.g., bounced between services; poor interaction between child and adult services; argument over who is responsible for funding).

Table 41 ranks the 10 most frequently reported categories of problems that autistic people experience in relation to using, or trying to access, mental health services. The data are ranked from most frequently reported to least frequently reported problems across all respondents. The right-hand columns report the proportion of specific respondent groups that identified this as a problem. Note that respondents often identified within multiple groups (e.g., autistic and a parent/caregiver of an autistic child), so the total of the subgroups will exceed the total number of all respondents.

Of note is that these data show that approximately:

1 in 4 respondents highlight that there is insufficient availability or access to relevant, skilled mental health workers.

1 in 4 respondents highlight that mental health workers have limited knowledge or understanding of autism/neurodiversity, its presentation, and its impact across the lifespan.

It is important to acknowledge that challenges associated with mental health crisis support was identified as a problem within the mental health service by 4% of respondents. When autistic people are experiencing crisis, they find there are limited crisis services, and those that are available lack quality (e.g., do not follow through on promised support; rely on phone calls which may not be a preferred or accessible contact method for autistic people).

Table 41: 10 most frequently reported problems experienced by autistic people in relation to using or trying to access mental health services

Rank	Problems experienced by autistic people in relation to using or trying to access mental health services and sample quotes from responses	Direct insight	Respondents who stated this as a problem					
			All respondents *N* = 539	Autistic people n = 250	Family member/ caregiver of autistic person n = 327	Mental health professionals n = 75	Medical and allied health professionals n = 130	Other respondent groups* n = 192
1	**Insufficient availability/access of relevant, skilled mental health worker** (e.g., lack of providers who can do assessments; challenges finding neurodivergent therapist)	*"Not enough access to Occupational Therapists who can help open the door to more needed mental health help."* (ID 153) *"Access to enough psychologists for assessments and therapies because only a small number of psychologists are endorsed 'clinical'."* (ID 555)	24%	18%	27%	21%	22%	21%
2	**Lack of knowledge or understanding of autism/neurodiversity, its presentation, and its impact across the lifespan** (e.g., lack of knowledge about autism in females; lack of understanding of lived experience)	*"Very few psychologists understand autism. Even fewer understand pathological demand avoidance. Psychologists who don't understand autism can cause harm."* (ID 955) *"Most mental health service practitioners do not have enough knowledge about autism (especially as it presents in women) to be able to tailor mental health support appropriately."* (ID 1159)	23%	28%	22%	29%	24%	21%

Rank	Problems experienced by autistic people in relation to using or trying to access mental health services and sample quotes from responses	Direct insight	Respondents who stated this as a problem					
			All respondents *N* = 539	Autistic people n = 250	Family member/ caregiver of autistic person n = 327	Mental health professionals n = 75	Medical and allied health professionals n = 130	Other respondent groups* n = 192
3	**Prohibitive cost** (e.g., very expensive; services able to charge too much)	*"I am horrified by the concept of 'bulk billing' and 'gap fees' - Australia is meant to be a First World country. Waiting lists are to be expected, but many people who need mental health support the most have given up hope of ever accessing support because they can't afford the gap fee."* (ID 68) *"Costs can be prohibitive for some families given the long-term nature of mentoring required for some clients."* (ID 380)	22%	28%	22%	12%	15%	23%
4	**Long or closed waitlists** (e.g. long waiting time to access diagnostic services, psychologists, and psychiatrists; waiting lists exacerbate issues)	*"General wait time to start seeing a psychiatrist in our area is 18 months. It took 8 months for us to get an appointment with [a] psychologist."* (ID 30) *"Mine is the wait time. I needed to see/ talk to my psychotherapist with an issue in early March. My appointment is in mid May."* (ID 1329)	21%	19%	24%	9%	15%	22%

Rank	Problems experienced by autistic people in relation to using or trying to access mental health services and sample quotes from responses	Direct insight	Respondents who stated this as a problem					
			All respondents *N* = 539	Autistic people n = 250	Family member/ caregiver of autistic person n = 327	Mental health professionals n = 75	Medical and allied health professionals n = 130	Other respondent groups* n = 192
5	**Insufficient availability/access of appropriate services** (e.g., lack of services specialising in autism; long distance to travel)	*"Services [are] often geographically difficult to access requiring children to miss a lot of school to attend appointments and parents to miss work to drive children to and from appointments (in my case having to move to part-time work to support driving my child to appointments)"* (ID 1131)	20%	17%	19%	17%	18%	23%
6	**Misdiagnosis of autism and/or co-occurring conditions** (e.g., misdiagnosing autism as, for example, a personality disorder; diagnostic overshadowing)	*"I've been in and out of therapy my whole life, at one point was diagnosed with emotional [deprivation] disorder. I had an inkling when my daughter was small and I saw it in her then [realised] it was me too. I think I suggested it in therapy but it must have seemed absurd to the psychologist. Now I know, and I know my (dec) partner was autistic and that my mum likely is and so on."* (ID 477) *"I've seen professionals for years and been misdiagnosed with anxiety, social anxiety, depression, and PTSD. I have none of these conditions."* (ID 1346)	10%	12%	9%	13%	11%	9%

Rank	Problems experienced by autistic people in relation to using or trying to access mental health services and sample quotes from responses	Direct insight	Respondents who stated this as a problem					
			All respondents *N* = 539	Autistic people n = 250	Family member/ caregiver of autistic person n = 327	Mental health professionals n = 75	Medical and allied health professionals n = 130	Other respondent groups* n = 192
7	**Lack of knowledge or understanding of the interaction between autism and co-occurring conditions including mental health problems** (e.g., lack of knowledge of mental health issues and experiences for autistic people; lack of understanding of co-occurring conditions including ADHD and mental health)	*"Finding a competent mental health professional that really understands the autistic experience of comorbid conditions such as anxiety, OCD, depression - that the autistic expression of these conditions may be different, especially if they also have intellectual disability."* (ID 91)	7%	6%	7%	7%	9%	7%
8	**Strategies not tailored for the individual client or neurodivergent people** (e.g., not tailored for individual needs or preferred goals; neurotypical strategies do not always work for autistic people)	*"Mental health workers often try to use regular interventions like CBT which isn't always suitable for neurodivergent people, or they're not well versed in what autistic people actually need. One example is being asked 'Where do you feel that in your body?' Well, autistic people sometimes don't feel like things hunger etc, how can we be expected to know where we feel a feeling, that usually we struggle to even name the feeling in the first place."* (ID 288)	7%	10%	6%	3%	5%	7%

Rank	Problems experienced by autistic people in relation to using or trying to access mental health services and sample quotes from responses	Direct insight	Respondents who stated this as a problem					
			All respondents *N* = 539	Autistic people n = 250	Family member/ caregiver of autistic person n = 327	Mental health professionals n = 75	Medical and allied health professionals n = 130	Other respondent groups* n = 192
9=	**Access refused due to autism diagnosis** (e.g., refusal of autistic client for fear of doing harm; services do not support autistic people)	*"CAMHS [Child and Adolescent Mental Health Service - WA] refusing to support children and teenagers with ASD who also have mental health concerns. Referrals are often knocked back purely on the basis of disability without taking into account the individuals mental health needs."* (ID 410) *"Professionals may feel fearful of doing harm and therefore refuse to see individuals with autism, restricting [the] number of providers able to assist."* (ID 643)	6%	4%	7%	12%	12%	8%
9=	**Challenges accessing services due to lack of support, knowledge, or accommodations** (e.g., challenges navigating the services; challenges booking appointments by telephone)	*"Executive dysfunction that some autistic people experience can mean that finding a psychologist with availability and expertise can take a very long time or assistance is required from a support person. It can mean sending emails about appointments or reports can take weeks or months to send, which for a neurotypical person could take 5 minutes."* (ID 873) *"It's always phone calls to try and access services so I often just don't."* (ID 1081)	6%	6%	6%	9%	3%	9%

Rank	Problems experienced by autistic people in relation to using or trying to access mental health services and sample quotes from responses	Direct insight	Respondents who stated this as a problem					
			All respondents *N* = 539	Autistic people n = 250	Family member/caregiver of autistic person n = 327	Mental health professionals n = 75	Medical and allied health professionals n = 130	Other respondent groups* n = 192
9=	**Professionals may make assumptions or have preconceived ideas of autism, holding a deficit based view** (e.g., stereotyping; behaviours viewed as attention seeking)	*"The surprise when health professionals finally see me when my disability becomes impactful because of increased stress as [they] assume that I wasn't as disabled as I told them."* (ID 940)	6%					

Note. *all other groups that have not been identified separately

3.7.1.2 Factors causing the problems experienced by autistic people when using, or trying to access, the mental health service

A total of 452 respondents opted to answer this question on using, or trying to access, mental health services. This included 213 autistic people and 280 family members or carers of autistic people. The factors that respondents felt were causing or leading to the problems experienced by autistic people when using, or trying to access, mental health services were coded into 19 categories, which fall under the following 11 broad areas:

- Lack of, and poor quality of, autism training available for mental health professionals
- Lack of autism-relevant knowledge and skills held by mental health professionals
- Insufficient access to relevant professionals or services
- Challenges accessing funding for mental health purposes
- Problems within the mental health sector
- Strategies considered insufficient, inappropriate, or poor quality
- Negative impact of decisions made by the government
- The lack of knowledge base and deficit-based assumptions of practices
- Challenges around diagnosis
- Preconceived ideas and stereotypes of autism held by professionals
- Impact of autism characteristics (or associated characteristics) on therapy.

Table 42 ranks the 10 most commonly reported factors that respondents felt were causing the problems that autistic people experience in relation to using, and trying to access, mental health services reported above. The data are ranked from most frequently reported to least frequently reported problems across all respondents. The right-hand columns report the proportion of specific respondent groups that identified this as a problem. Note that respondents often identified within multiple groups (e.g., autistic and a parent/caregiver of an autistic child), so the number of respondents in subgroups exceeds the total number of all respondents.

Importantly, these data show that approximately:

1 in 4 respondents stated that the problems were due to lack of, or poor quality of, training for mental health professionals.

1 in 4 respondents reported that the problems were due to staff in mental health settings having insufficient knowledge of autism and neurodivergent conditions, its presentation, and its impact.

Table 42: 10 most frequently reported factors causing the problems experienced by autistic people in relation to using or trying to access mental health services

Rank	Factors causing the problems experienced by autistic people in relation to using, or trying to access, mental health services and sample quotes from responses	Direct insight	Respondents who stated this as a problem					
			All respondents *N* = 452	Autistic people n = 213	Family member/ caregiver of autistic person n = 280	Mental health professionals n = 70	Medical and allied health professionals n = 118	Other respondent groups* n = 170
1	**Lack of, or poor quality of, training for mental health professionals** (e.g., poor training; lack of training in diagnosing and treating autism appropriately)	*"Lack of education leads to a lack of accommodations leading to a lack of appropriate care for neurodiverse people."* (ID 162) *"Psychologists and mental health professionals have not been taught about autistic mental health from autistic made sources."* (ID 816)	23%	27%	17%	39%	29%	22%
2	**Lack of knowledge or understanding of autism and neurodivergent conditions, its presentation, and its impact** (e.g., lack of understanding the heterogeneous presentation of autism; lack of understanding of stresses associated with autism)	*"Lack of understanding that autism can be 'missed' in childhood, but masking 'hides' issues- especially for biological women."* (ID 842)	22%	28%	22%	31%	28%	20%
3	**Insufficient number of professionals with an interest/expertise in autism** (e.g., lack of qualified people specialising in autism; lack of specialists in rural areas)	*"There aren't enough general psychologists let alone any that specialise in autism."* (ID 41)	19%	12%	20%	13%	17%	19%

Rank	Factors causing the problems experienced by autistic people in relation to using, or trying to access, mental health services and sample quotes from responses	Direct insight	Respondents who stated this as a problem					
			All respondents *N* = 452	Autistic people n = 213	Family member/ caregiver of autistic person n = 280	Mental health professionals n = 70	Medical and allied health professionals n = 118	Other respondent groups* n = 170
4	**Insufficient funding (generally)** (e.g., lack of funding; funding shortfall)	*"Too expensive. Some don't have NDIS but can't afford support, as rates are charged at NDIS prices with no acceptance of GP mental health plans or chronic disease management plans."* (ID 17)	19%	15%	20%	13%	19%	17%
5	**Concern about therapeutic skills and/or attitude** (e.g., lack of respect; ableism; not allowing time to develop relationship; ignorance)	*"Busy staff ... just ticking boxes etc, without any empathy or humility or desire to truly help improve peoples' lives."* (ID 147) *"Focus on quickly getting assessments and diagnosis rather than relationship and rapport building to understand what the individual's baseline is, and lack of critical engagement with family/caregivers."* (ID 998)	13%	17%	13%	13%	13%	12%
6	**Overwhelmed system/professionals with insufficient resources** (e.g., lack of resources; overwhelmed staff; time pressure)	*"EXTREMELY limited resources dedicated to supporting autistic people in a meaningful manner."* (ID 784) *"System overburden and burnout. Clinicians have high caseloads and are time poor. Complexity associated with autism and greater time commitment results in greater unwillingness to work with Autistic people."* (ID 1357)	10%	7%	11%	9%	8%	11%

Rank	Factors causing the problems experienced by autistic people in relation to using, or trying to access, mental health services and sample quotes from responses	Direct insight	Respondents who stated this as a problem					
			All respondents *N* = 452	Autistic people n = 213	Family member/ caregiver of autistic person n = 280	Mental health professionals n = 70	Medical and allied health professionals n = 118	Other respondent groups* n = 170
7	**Strategies and practices considered insufficient, inappropriate, or poor quality** (e.g., lack of awareness of how to modify practices; neuronormative concepts of well-being applied to autistic people)	*"Mental health professionals profess to only 'treat the mental health condition' with no consideration of how neurodivergence is interwoven and part of the whole person."* (ID 354) *"The promotion of 'evidence based' treatments such as CBT and ABA - these do not work for most ND clients."* (ID 852)	10%	9%	10%	13%	14%	12%
8	**Impact of decisions made by the government** (e.g., government policies; government cuts; poor management of mental health services)	*"Poor government policy and intervention - need clear guidance, programs to ensure service availability, subsidies costs, and better designed medical and mental healthcare systems to ensure early diagnosis by frontline medical, educational or caregiver staff (diagnosis should not rely on self-diagnosed first!)."* (ID 1494) *"Gov't agencies playing a 'not my responsibility card' and yoyo'ing people between NDIS, Medicare, Private Health and Public Health."* (ID 1555)	9%	10%	8%	9%	8%	8%

Rank	Factors causing the problems experienced by autistic people in relation to using, or trying to access, mental health services and sample quotes from responses	Direct insight	Respondents who stated this as a problem					
			All respondents *N* = 452	Autistic people n = 213	Family member/ caregiver of autistic person n = 280	Mental health professionals n = 70	Medical and allied health professionals n = 118	Other respondent groups* n = 170
9	**Lack of knowledge, understanding, or experience of co-occurring conditions including mental health, and their interaction with autism** (e.g., lack of knowledge about, or experience with, mental health conditions, autistic burnout)	*"The actions of mental health services and staff just cause more trauma to people with autism. They are incapable of handling me as one human being who has autism, two serious mental illnesses and several chronic physical illnesses."* (ID 1436)	8%	7%	8%	9%	9%	10%
10	**Insufficient number of, or access to, services** (e.g., lack of services/facilities; gatekeeping; distance for rural people)	*"Gatekeeping in psychology training and registration artificially decreasing the number of psychologists."* (ID 724)	8%	6%	7%	3%	9%	12%

Note. *all other groups that have not been identified separately

3.7.1.3 Factors that could prevent or reduce the problems experienced by autistic people when using, or trying to access, mental health services

A total of 422 respondents opted to answer this question on using, or trying to access, mental health services. This included 250 autistic people and 264 family members or carers of autistic people. The factors that respondents identified as preventing or reducing the problems experienced by autistic people when using, or trying to access, mental health services were coded into 14 categories. These categories fall under the following eight broad areas:

- Training and education for mental health professionals
- More providers and access to mental health services
- Reduced financial barriers
- Enhanced relevant therapeutic skills tailored to autistic clients
- Changes to practice to focus on strengths, neurodiversity affirming care, and skills relevant to supporting autistic people
- Government reform and support of mental health sector
- Improve communication and integration between professionals and/or sectors
- Co-developed research to develop an evidence base to enhance understanding of autism and practices appropriate for neurodivergent people.

Table 43 ranks the 10 most commonly reported factors that respondents reported could prevent or reduce the problems that autistic people experience in relation to using, or trying to access the mental health services reported above. The data are ranked from most frequently reported to least frequently reported problems across all respondents. The right-hand columns report the proportion of specific respondent groups that identified this as a problem. Note that respondents often identified within multiple groups (e.g., autistic and a parent/caregiver of an autistic child), so the number of respondents in subgroups exceeds the total number of all respondents.

Importantly, these data show that there was a clear, predominant factor highlighted by respondents:

Over 2 of every 5 respondents identified training in autism as a factor that could prevent or reduce the problems experienced by autistic people when using, or trying to access, mental health services.

Table 43: 10 most frequently reported factors that could prevent or reduce the problems experienced by autistic people in relation to mental health services

Rank	Factors that could prevent or reduce the problems experienced by autistic people in relation to using or trying to access mental health services and sample quotes from responses	Direct insight	Respondents who stated this as a problem					
			All respondents *N* = 422	Autistic people n = 250	Family member/ caregiver of autistic person n = 264	Mental health professionals n = 65	Medical and allied health professionals n = 111	Other respondent groups* n = 154
1	**Increase (access to) training for people working as mental health professionals to enhance their understanding of autism (and other neurodivergence), including training from autistic people with lived experience** (e.g., mandatory, regular training; autistic informed/delivered training)	*"Better education of training psychologists both to better understand autism and its different presentations and best evidence therapies for autistic clients and of neuro affirming practices. Ideally this should come from the voices of the handful of autistic psychologists currently practicing that are leading this movement."* (ID 90)	42%	46%	40%	45%	47%	36%
2	**More mental health professionals, including those specialising in autism, and those who are autistic/ neurodivergent themselves** (e.g., more doctors; more psychologists; create new roles and professions to support autistic people; incentives for experts; alternative qualification pathways)	*"Government to address the lack of psychological services in the community i.e. allow provisional psychologists to be covered by Access to Mental Health Care plan sessions to increase numbers in the community and continue to improve services."* (ID 1204)	20%	19%	21%	22%	23%	21%

Rank	Factors that could prevent or reduce the problems experienced by autistic people in relation to using or trying to access mental health services and sample quotes from responses	Direct insight	Respondents who stated this as a problem					
			All respondents *N* = 422	Autistic people n = 250	Family member/ caregiver of autistic person n = 264	Mental health professionals n = 65	Medical and allied health professionals n = 111	Other respondent groups* n = 154
3	**Increase funding and/or affordability of mental health services across the lifespan** (e.g., government funded functional capacity assessment; price caps and/ or rebates)	*"The Government needs to properly fund mental health services, so that when autistic people need their services, they are not simply referred back to their NDIS providers."* (ID 532) *"Somehow reducing the cost of things like therapy and having more psychologists/ positions for psychologists available."* (ID 882)	19%	19%	21%	11%	18%	21%
4	**Improve access to, and quality of, services** (e.g., reduce the red tape; consideration of access for regional and rural areas; services for people with complex needs)	*"Have more mental health services available for transition from early childhood, to primary and secondary school, then a big increase at [the] end of high school. Transition to adult services when done effectively early, will ultimately benefit the young person with Autism and also place less strain on the medical system down the track."* (ID 559) *"There should be the ability to access psychosocial support whenever needed once a diagnosis is given. Kind of like an unlimited referral that sometimes can be given for other specialists."* (ID 963)	12%	9%	11%	19%	10%	12%

Rank	Factors that could prevent or reduce the problems experienced by autistic people in relation to using or trying to access mental health services and sample quotes from responses	Direct insight	Respondents who stated this as a problem					
			All respondents *N* = 422	Autistic people n = 250	Family member/ caregiver of autistic person n = 264	Mental health professionals n = 65	Medical and allied health professionals n = 111	Other respondent groups* n = 154
5	**Enhance the quality of university education and number of places availability** (e.g., do not phase out psychology general registration pathway; provide education on neurodiversity-affirming practice; include information on co-occurring intellectual disability and other co-occurring conditions)	*"Increase the number of university places for mental health professionals - especially psychologists AND ensure the general registration pathway (honours degree + 2-year internship) pathway is not phased out."* (ID 60) *"Psychology and psychiatry curricula need mandatory information about autism."* (ID 1092)	11%	9%	11%	14%	14%	11%
6	**Enhance the therapeutic skills and awareness of mental health professionals to support their work with autistic clients** (e.g., listen to [and believe] the client to identify challenges; account for possible challenges in identifying emotions or forming trust)	*"Listening to the individual or working their psych magic to discover what's not ok and changing course when required. Giving time and space. Being creative. I've learnt a lot with toys and characters and truly benefit from a psychologist who helped me by using early childhood things like a 'circle of friends'."* (ID 185)	10%	11%	9%	9%	12%	14%

Rank	Factors that could prevent or reduce the problems experienced by autistic people in relation to using or trying to access mental health services and sample quotes from responses	Direct insight	Respondents who stated this as a problem					
			All respondents *N* = 422	Autistic people n = 250	Family member/ caregiver of autistic person n = 264	Mental health professionals n = 65	Medical and allied health professionals n = 111	Other respondent groups* n = 154
7	**Facilitate changes to practice to focus on strengths, neurodiversity affirming care, and skills relevant to supporting autistic people** (e.g., use social model rather than medical model; neurodiversity affirming practice)	*"Stop looking at behaviour and search for unmet needs."* (ID 17) *"Use of universal strategies that would enable any struggling individual to thrive - soothing environment, reduced demands, genuine relational basis, thorough skill building, individually tailored program. NOT providing short term superficial and inconsistent program or supports that reinforce fear of change and experience of failure."* (ID 581)	10%	10%	11%	17%	6%	12%
8	**Make access and use of services easier and more autism-friendly** (e.g., alternative methods to book appointments, increased flexibility of appointments; environment)	*"Autistic people need more options around the structure and timing of mental health appointments, such as shorter, more frequent appointments, or appointments that are not conducted in real time (like audio message appointments)."* (ID 290) *"Ensure that clinics and such are warm, welcoming spaces that are sensitive to the sensory needs of people with autism."* (ID 1004)	9%	10%	8%	11%	5%	9%

Rank	Factors that could prevent or reduce the problems experienced by autistic people in relation to using or trying to access mental health services and sample quotes from responses	Direct insight	Respondents who stated this as a problem					
			All respondents *N* = 422	Autistic people n = 250	Family member/ caregiver of autistic person n = 264	Mental health professionals n = 65	Medical and allied health professionals n = 111	Other respondent groups* n = 154
9	**Implement NDIS specific improvements for funding access** (e.g., more inclusive funding; automatic access to NDIS for autistic people)	*"NDIS needs to accept more high functioning autistic people and ALWAYS APPROVE weekly psychology for autistic people."* (ID 81) *"My son is diagnosed with ASD, PDA, OCD, PTSD, and Cluster B personality disorder. He keeps falling through bureaucratic cracks because he receives the NDIS for Autism/OCD which doesn't cater to his mental health diagnoses."* (ID 1119)	7%	7%	8%	8%	8%	8%
10	**Implement Medicare-specific improvements for increasing affordability of mental health care** (e.g., allow provisional psychologists to work under Medicare; Medicare funding for mental health)	*"Medicare and state health service models need to move towards activity and funding models that accommodate and reward complex, integrated care."* (ID 373) *"Bring back the extra sessions available with a Medicare rebate on a mental health care plan."* (ID 1324)	7%	9%	5%	12%	10%	6%

3.7.1.4 Factors that are working well, or have worked well, for autistic people in relation to using or trying to access mental health services

A total of 322 respondents opted to answer this question on using, or trying to access, mental health services. This included 121 autistic people and 201 family members or carers of autistic people. The factors that, when available, are reported to be working well, or have worked well, for autistic people in relation to using to trying to access mental health services were coded into 12 categories, which fall under nine broad areas:

- Nothing/not a lot
- Finding the right mental health professional, including those with good therapeutic skills and lived experience
- NDIS once funding has been provided to support needs
- Alternative or flexible access (inc. making appointment and practice) when available
- Support from family, friends, and the autistic/neurodivergent community
- Having a range of practices including those that are neurodiversity-affirming
- Developing a safe, trusting therapeutic relationship
- Having a range of different services, including crisis helplines, autism-specific services, and community services
- Increased awareness of autism/neurodivergence and the benefits of mental health support.

Table 44 ranks the five most commonly reported factors that respondents reported to be working well, or have worked well, for autistic people in relation to using, or trying to access, mental health services. The data are ranked from most frequently reported to least frequently reported factors that are working well across all respondents. The right-hand columns report what proportion of specific respondent groups reported this as a factor that is working well or has worked well. Note that respondents often identified within multiple groups (e.g., autistic and a parent/caregiver of an autistic child), so the number of respondents in subgroups exceeds the total number of all respondents.

Importantly, these data show that approximately:

1 in 5 respondents felt that nothing or not a lot was working to support autistic people within mental health services.

Almost 1 in 5 stated that finding the right mental health professional for them was one factor that is working well in the mental health service. (NB. This was often accompanied by a statement regarding the need to hold onto that mental health professional at all costs.)

Table 44: 10 most frequently reported factors that are working well, or have worked well, in relation to autistic people using or trying to access mental health services

Rank	What is working well, or has worked well, in relation to autistic people using to trying to access mental health services and sample quotes from responses	Direct insight	Respondents who stated this as a problem					
			All respondents *N* = 322	Autistic people n = 121	Family member/ caregiver of autistic person n = 201	Mental health professionals n = 53	Medical and allied health professionals n = 79	Other respondent groups* n = 117
1	**Nothing/Not a lot**	*"In our experience of accessing mental health services for our son, I can honestly say that there has been nothing that has worked well. We have been constantly left trying to navigate/ fight a broken system, whilst trying to keep our son alive."* (ID 48) *"Nothing is working well, the cost is unaffordable and the waiting times are causing higher rates in suicide and trips to the ER where they are not receiving sufficient help with mental health, only a band aid solution and sent home with tablets."* (ID 528)	21%	25%	23%	9%	18%	24%
2	**When you find the right mental health professional for you, who is often knowledgeable/experienced about autism and its associated needs** (e.g., understands autism and neurodiversity; experience working with autistic people)	*"Extremely well trained and experienced mental health practitioners and psychologists are a godsend. Just brilliant."* (ID 935) *"When you find an attuned social worker/psychologist who really 'gets' what it is like to be autistic and the level of anxiety that can permeate every aspect of daily life, you can really start to make therapeutic headway into teaching/learning strategies that will support during a crisis."* (ID 963)	19%	18%	16%	26%	24%	20%

Rank	What is working well, or has worked well, in relation to autistic people using to trying to access mental health services and sample quotes from responses	Direct insight	Respondents who stated this as a problem					
			All respondents *N* = 322	**Autistic people** n = 121	**Family member/ caregiver of autistic person** n = 201	**Mental health professionals** n = 53	**Medical and allied health professionals** n = 79	**Other respondent groups*** n = 117
3	**When NDIS funding has been provided to support needs** (e.g., NDIS can reduce mental health challenges when all needs are covered; supportive NDIS plan manager)	*"NDIS supports can generally and holistically reduce mental health burden when all needs are covered and assisted with. Prevention is better than cure. In this way NDIS is fantastic and will probably save the government money due to less crisis intervention later down the track."* (ID 60) *"NDIS has provided a new method for autistic individuals who are supported by the NDIS to access psychology services without personal financial cost."* (ID 1203)	15%	13%	13%	21%	22%	15%
4	**When alternative/flexible access are available (inc. making appointment and practice)** (e.g., online chat services; alternative booking options such as leaving voice message or online portal)	*"More mental health practitioners are offering flexible appointment structures using tools like online portals where patients can upload images/writing, and audio message programs like Voxer."* (ID 290) *"Access to Telehealth services is an important step forward, particularly for autists, and family members who may experience anxiety related conditions and/or depression."* (ID 937)	10%	13%	11%	6%	3%	12%

Rank	What is working well, or has worked well, in relation to autistic people using to trying to access mental health services and sample quotes from responses	Direct insight	Respondents who stated this as a problem					
			All respondents N = 322	Autistic people n = 121	Family member/ caregiver of autistic person n = 201	Mental health professionals n = 53	Medical and allied health professionals n = 79	Other respondent groups* n = 117
5	**Support from family, friends, and autistic/neurodivergent community** (e.g., parent advocacy; ability to bring trusted person to appointments; social groups to meet other autistic people)	*"The best thing I experienced was going to an Aspergers support group for adults on the spectrum."* (ID 406) *"Parents who can afford private services. Parents who jump up and down and push for access. Parents who advocate."* (ID 773)	8%	8%	9%	4%	5%	9%
6	**When a professional has lived experience** (e.g., are autistic/neurodivergent, or have autistic family members)	*"I am happy to say that I can now access a psychologist through my NDIS plan and the best thing is they are on the spectrum themselves so I am really comfortable talking to them, however this has not always been the case."* (ID 400) *"I happened to have an autistic psychologist once and he was the most helpful psychologist I have ever had. I had never really made any progress with counseling before and usually it made me feel worse so I would stop going. Just from my experience I would say that an autistic psychologist is better for an autistic person, than a neurotypical psychologist."* (ID 1328)	7%	10%	6%	8%	9%	7%

Rank	What is working well, or has worked well, in relation to autistic people using to trying to access mental health services and sample quotes from responses	Direct insight	Respondents who stated this as a problem					
			All respon-dents *N* = 322	Autistic people n = 121	Family member/ caregiver of autistic person n = 201	Mental health profession-als n = 53	Medical and allied health profession-als n = 79	Other respondent groups* n = 117
7=	**The recent shift towards neurodiversity affirming and strengths-based practice, rather than relying on medical model** (e.g., focus on the strengths of a person rather than the challenges)	*"Focusing on the person's well-being and how to support improved well-being rather than functioning like [a neurotypical]."* (ID 164) *"Psychologists who write things like 'Mary thrives in fast-paced environments' to describe an extremely ADHD autistic person! Such professionals can really help identify areas that the autist will thrive in long-term."* (ID 1269)	7%	9%	8%	9%	13%	8%
7=	**A range of different approaches and modifications highlighting that no single approach is suitable for everyone** (e.g., trauma-informed; assistance animals; art therapy; social skills sessions; psychotherapy; group sessions)	*"Professionals who are flexible and use alternative methods such as Equine therapy, using an assistance dog, OTs that have gym equipment for regulation during session[s]. The traditional 'talking' therapy doesn't work."* (ID 359) *"Art, music, activities in sessions - making art in therapy is helpful because it externalises the focus of therapy onto the art object. [...]. Engaging senses in soothing activities also helps contain and nourish people so that they don't feel as exposed and they can feel calmer."* (ID 897)	7%	6%	8%	11%	1%	7%

Rank	What is working well, or has worked well, in relation to autistic people using to trying to access mental health services and sample quotes from responses	Direct insight	Respondents who stated this as a problem					
			All respondents *N* = 322	Autistic people n = 121	Family member/ caregiver of autistic person n = 201	Mental health professionals n = 53	Medical and allied health professionals n = 79	Other respondent groups* n = 117
7=	**When you develop a safe, trusting, therapeutic relationship** (e.g., feeling safe; building long-term relationship; continuity of care)	*"Seeing the same person locally for some years has been really helpful to make progress, it takes months to warm up to a new person."* (ID 942) *"Once you find 'your person', the neurodivergent person feels safe and things can change [improve]."* (ID 974)	7%	5%	7%	9%	6%	5%
10	**When a professional has good therapeutic skills** (e.g., compassionate, flexible, listens, patient, speaking calmly)	*"Speaking calmly and patience."* (ID 858) *"An empathetic person... Someone who can prompt or assist them to complete all the necessary steps instead of giving up due to depression."* (ID 1481)	5%	6%	7%	8%	5%	4%

Note. *all other groups that have not been identified separately

3.7.2 Umbrella review

An umbrella review is a form of research that brings together the findings of all existing reviews (systematic and scoping) that report on a specific topic. The focus of this review is on the mental health service itself (e.g., providers, delivery method), rather than on specific therapies offered when an autistic person is within a mental health service. The terms used for the searches and the number of articles identified, screened, and included are provided in Appendix J-1 and Appendix J-2**.** The final umbrella review reports on 14 systematic reviews, five of which were led by Australian authors. All of these systematic reviews were written in the last 5 years. The 14 systematic reviews collectively report on 391 individual studies.

The information and findings from the included reviews are summarised in the subsections below. When reporting on the number of people or participants in the review, this will be represented as *n* = [number of participants]. When reporting on the number of reviews that considered a topic, this will be represented as *k* = [number of reviews].

3.7.2.1 Participants within included reviews

In total, the reviews included 7,626,660 participants, with sample size for individual studies ranging from 1 to 6,724,857 (*M* = 635,555; *SD* = 1,924,556.93). Of these participants, 202,953 (2.66%) were reported to be autistic. Only seven systematic reviews provided information on the gender of autistic participants; most of the autistic participants in these reviews were male (average percentage = 71.24%) and ranged in age from 0 to 100 years.

3.7.2.2 Quality of included reviews

The quality of the included systematic reviews was assessed using the JBI Critical Appraisal Tool for Systematic Reviews. This tool assesses the methodological quality of a systematic review. The maximum score is 33, which indicates a very high-quality systematic review. The average quality score for the 14 included systematic reviews was 27.64 (84%), with the quality score ranging from 21 to 32.

3.7.2.3 Topics of included reviews

The 14 reviews identified in the area of autism and mental health services can be summarised across four key topics. These were barriers and facilitators to accessing mental health services (*k* = 8 reviews); mental health practitioners: autism training, knowledge, and experience (*k* = 4); service use and predictors of service use (*k* = 3 reviews); and technology and telehealth in mental health services (*k* = 4). The key findings for each topic are presented in Table 45.

3.7.2.4 Research gaps

After reading the 14 reviews, the research team identified a number of key research gaps. These are combined with the relevant research gaps noted within the reviews themselves, and summarised in Table 45.

There is limited research documenting the mental healthcare needs of autistic people in Australia; met and unmet. The majority of the research looking at mental health services for autistic people describes the experiences of autistic adults or parents of autistic children, so there is a need to document the views and experiences of autistic young people accessing mental health services.

Within the mental health systems, there is the potential to research autism-specific pathways, with models of such pathways being documented in the UK and USA. There is also limited research exploring autistic people's use of and experiences with informal mental health supports, such as helplines or digital mental health supports. These informal supports are becoming increasingly critical given the long waiting lists for formal mental health supports. There was a consistent finding that mental health care professionals lack knowledge of autism, and ways to tailor their approach to support autistic people. This highlights the need for research to address this issue through co-developed and co-delivered training, the impact of which should be assessed through subjective and objective methods.

Table 45: Umbrella review findings for mental health services

Topic	Number of reviews on topic; citations	Key findings	Key research gaps identified
Barriers and facilitators to accessing mental health services	*k* = 8 Adams & Young (2021)* Anderson et al. (2022) Brede et al. (2022) Cameron et al. (2021)* Cleary et al. (2022a)* Cleary et al. (2022b)* Dickson et al. (2021) Hartley et al.* (2022)	• Frequently reported barriers (noted in reviews of community perspectives and intervention trials) include – practitioner/professionals' lack of autism knowledge or their lack of tailoring approaches to autism – waiting lists – time/appointment scheduling – not meeting inclusion criteria – not being believed or mental health problems not seen as severe enough – unclear referral or access pathways – costs, including funding of service or insurance coverage – client motivation. • Barriers to continuity of care in mental health services from childhood to adulthood are similar: clinicians' perceptions and limited understanding of autism (specifically autism in adulthood), long waiting lists, (lack of) spaces available in the adult mental health services, and disengagement of the autistic individual • The large number of barriers lead many autistic people and their family members to believe that mental health services are unsuitable, inaccessible, and unable to meet autistic individuals' needs, which impacts upon their likelihood to seek help, especially for less significant issues • Facilitators to accessing mental health support include: – continuity of sessions/service provider – therapists adapting approach/intervention to meet clients' needs – therapist having knowledge of autism. • Two reviews identified studies which evaluated group-based services. Participants in these studies reported enjoying the group format to learn from peers and make connections	• Young autistic people's experiences of accessing mental health services to identify barriers/facilitators for engaging with mental health services • Development and evaluation of autism-specific mental health pathways in services which can be tailored based on client preference and/or need (e.g., individualised/group, face-to-face vs online, differing communication methods). Evaluation of pathways impact on engagement and outcomes • Evidence-based co-designed training and its impact on practitioner knowledge and their practical/clinical skills when supporting autistic clients • What is needed to support transition from child to adult mental health services in Australia's mental healthcare system • The potential for bridging formal with informal supports, including a potential role for autism-specific mental health hotlines or online chat support • Experiences of autistic people within specialist (but not autism-specific) services, such as Gender Dysphoria or Eating Disorder services

Topic	Number of reviews on topic; citations	Key findings	Key research gaps identified
Mental health practitioners: Autism training, knowledge, and experience	*k* = 4 Cameron et al. (2021) Coughlan et al. (2020) Crede et al. (2022) Dickson et al. (2021)	• As well as being identified as the most common barrier to accessing mental health services across multiple reviews, how much knowledge a practitioner had about autism, training related to autism, and practitioners' experience in supporting autistic clients was discussed in three reviews • GPs achieved autism knowledge scores around 66%. GPs across multiple studies stated that they developed their autism knowledge from the media or from personal connections • Not all mental health practitioners feel confident in supporting the mental health needs of autistic individuals • Mental health practitioners may need to adapt approaches to support autistic clients, but due to a lack of evidence and training in how to do this, this can be inconsistent and ad hoc	• Evidence-based co-designed (and ideally co-delivered) training and its impact on practitioner knowledge as well as their practical/clinical skills when supporting autistic clients • Professionals' experiences of working with autistic young people with specific mental health conditions (e.g., depression) and what they use to make clinical decisions • Empirical data on effectiveness and acceptability of adaptations to mental health approaches (e.g., changing from small group to individual session, shortened session, etc.) • Provider knowledge of autism-specific presentations of mental health problems and how such presentations are monitored in the absence of autism-specific measures of mental health • How more autistic people can become accredited to provide mental health supports to autistic people
Autistic people's use of, and predictors of the use of, mental health services	*k* = 4 Anderson et al. (2022) Cleary et al. (2022b)* McBain et al. (2020) Smith et al. (2020)	• In the US, 44-69% of autistic children, and in Canada, up to 80% of autistic adults, used outpatient mental health services. Inpatient mental health services were used by 2-5% of American autistic children. No equivalent data are reported for Australia • In the US, 10-22% of autistic children have an unmet need relating to mental health. This proportion is even larger in those from racial or ethnic minority groups. No equivalent data are reported for Australia • Some autistic children, particularly those from racial or ethnic minority groups, are less likely to be referred to mental health services • Psychiatry-related visits to the emergency department are 9 times higher for autistic children than for non-autistic children in the US. No equivalent data are reported for Australia • Access to mental health services significantly reduces after transition from child to adult services; only 28% of young people in UK child mental health services are referred to adult mental health services. No Australian data were identified in that review. For those who do receive mental health support in adulthood, this is more likely to be psychiatry than psychology	• Data on Australian autistic individual's service use and unmet service needs • Evaluation of Australian autistic individuals' service use and unmet service needs by intersectionality (e.g., race, co-occurring conditions) • Workforce planning; current and future availability of providers to support mental healthcare needs of the increasing number of adults and older adults who identify as autistic

Topic	Number of reviews on topic; citations	Key findings	Key research gaps identified
Technology and telehealth in mental health services	*k* = 4 Cleary et al. (2022a)* De Nocker & Toolan (2021) Ellison et al. (2021) Valentine et al. (2021)	• The two systematic reviews focusing on telehealth for autistic individuals only identified two studies on telehealth for mental health. This is compared to over 30 studies which were identified on telehealth for behaviour and/or communication training • One study reported on the importance of using telehealth to develop a therapeutic relationship before face-to-face therapy. The second study reported on delivery of an anxiety intervention over telehealth; parents were equally satisfied in online vs. face-to-face version, despite 41% of parents of autistic children being disconnected during sessions at least once, and 6% reporting significant technological glitches • Mobile phone-based intervention improved adherence and engagement with autistic adolescents accessing services for depression	• The acceptability and feasibility of Australian autistic people, or their family members, receiving mental health supports over telehealth, or via digital mental health supports • Co-development and evaluation of autism-specific digital mental health supports for autistic people. This would likely have to be specific for age group as well as mental health focus (e.g. prevention, intervention for each mental health condition etc.)

* Denotes review led by Australian author.

Note: Co-development in this context means with the autistic and autism community and with people who will receive the training (i.e., educational staff)

3.7.3 Policy and guideline review

To capture a broad range of policies and guidelines at a national and/or state/territory-based level, a series of internet searches were conducted (see Appendix J-4 for more information). The policies and guidelines identified came covered a range of sectors or professions relevant to mental health services, including Australian federal government, state/territory level government, Australian Health Practitioner Regulation Agency, Australian Association of Social Workers, National Association of Aboriginal and Torres Strait Islander Health Workers and Practitioners, and Royal Australian and New Zealand College of Psychiatrists. Information within the identified policies relevant to autistic individuals or people with disability is summarised in Table 46**.**

Twenty-two policies and guidelines were identified, all of which were published or updated between 2008 and 2022, with 68% (*k* = 15) published in the last five years (2018 to 2023). Seventeen documents (77%) included provided some information relevant to individuals with disabilities; only 10 (45%) provided information directly relevant to autistic individuals. The policies summarised in Table 46 were distributed across national and state/territory level with nine from a national level, one from Australian Capital Territory, two from New South Wales, three from Queensland, one from Northern Territory, one from South Australia, one from Tasmania, one from Victoria, and three from Western Australia. While additional policies were considered during this review, only those that provided: a) information relevant to either autistic people or people with disability; and b) additional unique information over and above that already summarised in Table 46 were included.

Of note, there were six sectors/professions for which policies or guidelines relevant to autism were not identified during the search process. These consisted of occupational therapy, psychology, psychotherapy, pharmacy, community mental health care, and crisis support websites and phonelines. This may indicate that autism-related policies or guidelines are not available for that sector/profession, they are available only for individuals working within the profession, or they are difficult to access. The latter suggests that people working in, or interested, in this sector or profession may have difficulty accessing information that may assist in supporting autistic people.

3.7.3.1 Policy and guideline relevant to autistic people

The 10 documents that specifically discussed information pertinent to autistic individuals highlighted that within mental health services:

- Autistic people have been identified as experiencing higher rates of mental health conditions, with these mental health needs often unmet
- A range of barriers to accessing healthcare services have been identified, with policy and guidelines suggesting ways to minimise some of these barriers:
  - Ensure that information in communicated in an accessible way (e.g., verbal, written, Easy English, different colours or fonts)
  - Telehealth has been permanently incorporated into Medicare benefits scheme, supporting alternative methods to access mental health service.
- Collaboration can enhance mental health services for autistic individuals, this includes integration between federal and state services systems, and between professionals (e.g., discussing current medication and sensory consideration with treating paediatrician)
- Ensure an inclusive, person-centred approach that fosters a person's autonomy and provides

- an opportunity for active participation in decisions about one's care is used
- Provide training on autism to all professionals to support (a) timely autism diagnosis; (b) mental health outcomes; and (c) accessibility to mental health services
- More research is needed to further understand the mental health needs and outcomes of autistic people
- It is pertinent to include the perspective of autistic people in discussions about mental health services to support an inclusive approach to policy development and service design.

3.7.3.2 Policy and guideline relevant to people with disability

The 17 polices and/or guidelines that provided information pertinent to individuals with disabilities revealed that within mental health services:

- Disability is the result of the interaction between an individual with impairments and the structure/processes of society. As such, the focus should be on structural and cultural factors that may negatively impact on the individual to engage in the world
- People with disability have increased rates of mental health conditions, associated with complex needs and unique obstacles to accessing care. Moreover, indigenous Queenslanders are more likely to experience disability than non-indigenous Queenslanders
- Increased rates of mental health experienced by people with intellectual disability may be associated with complex needs and unique obstacles to accessing care
- Accessibility is key to supporting mental health of people with disability. Some examples include of how this can be supported include:
  - Communication using a range of methods (e.g., Easy English, written, verbal) that are free of jargon
  - Buildings that are physically accessible, which may include considering the sensory aspect of the building
  - Accessible administrative processes (e.g., how follow-up appointments are made)
  - Considering whether the child/family may benefit from access to a trained advocate.
- Integration of services (e.g., mental health services and disability services), may improve mental health services
- Collaboration between services/professions, for example discussing current mental health plan and medication with treating doctor
- While all services should be accessible to people with disabilities, specialist inpatient and community services may be beneficial for people with intellectual disability and mental health conditions
- Improvements in data collection can inform service design and interventions for improved health outcomes
- Good practice involves:
  - A person-centred approach
  - Respecting diversity
  - Avoiding discrimination
  - Placing the interests and well-being of the patient first.

- Using evidence-based practice and quality services can support better mental health outcomes for people with disability
- Understanding of disability is important as behaviour of a person with intellectual disability may be misinterpreted as indicating mental health illness. Speaking with family members and/or carer etc. may assist in understanding the presenting behaviour.

Table 46: Policy and guideline review findings for mental health services

Organisation level	Organisation name	Policy name	Policy date	Reference to autism	Reference to disability	Relevant information
Federal	Australian Government	Australian Government Response to the Select Committee on Autism (report): Services, support and life outcomes for autistic Australians	2022	✓	✓	• Agree in principle to better integrate federal and state service systems, including mental health mainstream systems, developing a National Roadmap for Improving Health Services for Autistic People • Permanent telehealth arrangements have been introduced to Medicare benefits scheme • 2021-22 budget provided $1 million over two years to continue to build the capacity of mental health workforce through education, training and health promotion to better meet the mental health needs of people with developmental disability, including autism • Suggestion that a National Autism Mental Health Plan is developed which would need to align with the National Mental Health and Suicide Prevention Agreement • If a National Autism Research Framework is supported by the Australian Government, the Department of Health and Aged Care will provide input into the health and well-being priority under the framework, including a focus on evaluation of mental health interventions for autistic people • Department of Health and Aged Care has allocated $9.3 million to deliver a pilot of specialised digital services for people with complex mental health needs, including intellectual disability and autism • National Roadmap for improving the health of people with intellectual disability to support health care professionals to provide better care for people with intellectual disability. In addition to people with a diagnosed or suspected intellectual disability, the Roadmap also includes autistic people with co-occurring intellectual disability.
National	Commonwealth of Australia	National Mental Health Policy	2008	×	✓	• Poor mental health can cause disability, with appropriate short and long stay accommodation options developed to prevent homelessness • Integrated partnership across housing, employment, education, youth affairs, police, community and disability services.
National	Medical Board Ahpra	Good Medical Practice: A code of conduct for doctors in Australia	2020	×	✓	• No discrimination on the grounds of disability.

Organisation level	Organisation name	Policy name	Policy date	Reference to autism	Reference to disability	Relevant information
National	Australian Association of Social Workers	AASW's Policy Position on Disability	2016	×	✓	• Disability represents the larger and more complex interaction between an individual with impairment and the structures and processes of society. It is not "physical, cognitive, or sensory impairments that cause disability, but rather the way in which societies fail to accommodate natural aspects of difference between people". Therefore, social workers adopt a person-in-environment approach that includes a focus on the structural and cultural factors that may negatively impact on an individual's ability to engage with the social world • The social work profession is committed to maximising the well-being of individuals, families, groups, communities, and society. It is considered that individual and societal well-being is underpinned by socially inclusive communities that emphasise principals of social justice and respect for human dignity and human rights. These values are in complete accord with the disability advocacy movement and the United Nations Convention on the Rights of Persons with Disabilities, which both inform the NDIS.
National	Nursing and Midwifery Board Ahpra	Code of Conduct for Nurses	2022	×	✓	• Adopt practices that respect diversity, avoid bias, discrimination and racism, and challenge belief based upon assumption (for example, based on gender, disability, race, ethnicity, religion, sexuality, age, or political beliefs) • Nurses must use expertise to protect and advance health and well-being of people with disabilities.

Organisation level	Organisation name	Policy name	Policy date	Reference to autism	Reference to disability	Relevant information
National	The Royal Australian and New Zealand College of Psychiatrists	Autism: Addressing the mental health needs of autistic people	2022	✓	✕	• This is a position statement addressing significant challenges and unmet mental health needs for people on the autism spectrum • Inclusive approach is required to support equitable access and equip mainstream services to meet the needs of autistic people • Specific mental health needs of autistic people must be considered in health services, systems, and practices • Psychiatrists aim to provide the best mental healthcare to autistic people experiencing barriers to mental healthcare • More research is needed to support people diagnosed in adulthood, and to support recognition and diagnosis for people who are female and people who are linguistically diverse • Equip all health, education, social, disability, and justice services to meet the needs of autistic people in planning service delivery and outcomes, inclusive of specialised capacity for those with more complex needs • Educate and train health providers in the mental health needs of autistic people • Consider the needs of autistic people within all relevant health, mental health and disability frameworks. Integrated, multidisciplinary approaches between sectors are required • Include the voice of autistic people to support a more inclusive approach to policy development and service design • Fund research on the specific mental health needs and health outcomes of autistic people to support improved service planning and interventions and reduce health discrepancies • A lack of understanding of autism and missed or misinterpreted diagnosis leads to inadequate or inappropriate treatment. An improved understanding of autism in clinicians working in mainstream services would improve experiences and outcomes for people who are or may be autistic, particularly as referrals via mainstream services are a common pathway to adult diagnosis.

Organisation level	Organisation name	Policy name	Policy date	Reference to autism	Reference to disability	Relevant information
National	The Royal Australian and New Zealand College of Psychiatrists	Intellectual Disabilities (ID): Addressing the mental health needs of people with ID	2022	×	✓	• This is a position statement rather than a policy but contains a lot of relevant information, a summary of which is below. • People with intellectual disability and mental health conditions should be considered in policy development particularly in the health, mental health, and disability sectors • Specialist inpatient and community services are required for people with intellectual disability and mental health conditions • All mainstream mental health services must be accessible to people with intellectual disability • Improved data collection is required to inform service design and interventions for improved health outcomes • People with intellectual disability require services to be delivered using a person-centred approach.
National	National Disability Insurance Scheme (NDIS)	Consultation Paper: Interventions for children on the autism spectrum	2021	✓	×	All health professionals should aim to: • Foster the person's autonomy, promote active participation in decisions about care and support self-management • Maintain continuity of individual relationships wherever possible • Ensure that comprehensive information about the nature of, and interventions and services for, people on the autism spectrum are available in appropriate language or formats including various visual, verbal and aural, easy-read, and different colour and fonts • Consider whether the child/family may benefit from access to a trained advocate.
National	Ahpra and National Boards	Code of Conduct	2022	×	✓	• Adopt practices that respect diversity, avoid bias, discrimination and racism, and challenge belief based upon assumption (for example, based on gender, disability, race, ethnicity, religion, sexuality, age or political beliefs) • Some patients have additional needs (e.g., those living with physical and/or cognitive disability). Good practice includes placing the interests and well-being of patient first, meeting mandatory reporting legislation about abuse and neglect, be aware of increased advocacy to ensure just access to healthcare, and when communicating treat patient with respect, encourage questions, provide information in a way the patient can understand, recognise the role of parents, carers or guardians, remain alert to patient who may be at risk.

Organisation level	Organisation name	Policy name	Policy date	Reference to autism	Reference to disability	Relevant information
State	Queensland Health	Evaluation of the Mental Health Act 2016 Implementation	2016	×	✓	• Improved patient rights and support, with Disability Advocacy Australia funded to deliver consumer and carer education • Improvement of how disability is supported in the court system.
State	Queensland Health	Aboriginal and Torres Strait Islander: Mental health strategy (2016-2021)	2016	×	✓	• Indigenous Queenslanders experience more ill-health and disability than non-indigenous Queenslanders • Aim to develop approach to working with a single care plan for people with mental health challenges that links mental health needs with any other community-based social and disability services they may require.
State	Queensland Health	Management of Patients with Acute Severe Behavioural Disturbance in Emergency Departments: Department of Health Guideline	2016	✓	✓	• Specific considerations should be made for patients with a disability such as “those with ID or ASD”. If possible, seek advice from patient’s treating Paediatrician/Psychiatrist or if transferring to another facility the accepting Paediatrician or Psychiatrist. Details should be sought on current medication plans, behaviour support plans, communication, plans/aides, and sensory considerations for the patients (particularly for those diagnosed with autism) • Use short clear statements which do not include medical jargon. The patient may not have the capacity to process information. For patients with a disability ensure communication aligns with the considerations in the patients’ communication plan.
State	NSW Health	Emergency Department Patients Awaiting Care	2018	×	✓	• Communication should be via a range of methods that accounts for the patient and family/carers understanding of information and any cultural, language, social, or disability requirements that are identified • When patients presenting to an emergency department are considered to be at risk, or who have a particular security need, a risk assessment to identify and address the identified security risks must be undertaken. These patients may include (but not limited to): patients with development disability; patients with mental health problems or “mental disorder” (sic).

Organisation level	Organisation name	Policy name	Policy date	Reference to autism	Reference to disability	Relevant information
State	The Sydney Children's Hospitals Network	Non-Restrictive Care for Mental Health Paediatric Inpatients with Co-Morbid Intellectual Disability and/or Autism Spectrum Disorder: Practice guideline	2019	✓	✓	• This is a detailed document, so key parts from the document summary have been provided below • NSW Health Child and Adolescent Mental Health services are committed to the Creating Positive Cultures of Care initiative, whose aims include the reduction of seclusion and restraint practices in inpatient units. The use of seclusion and restraint with patients should only be implemented as a last resort, where the patient poses danger to either themselves or others • Individuals with mental health and co-occurring intellectual disability and/or autism can pose a particular risk of escalated behaviours, due to vulnerabilities such as poorly developed communication skills, social relating and emotion regulation deficits, intellectual handicap, limited problem-solving skills, and sensory sensitivities • Proactive management for inpatients with these developmental disabilities is therefore essential, to ensure their rights to non-coercive, least-restrictive inpatient care are promoted, upheld, and protected.
Territory	ACT Health Directorate, Canberra	Future Directions of Disability Health in the ACT: Phase one of the ACT disability health strategy project	2021	×	✓	When working with people with disabilities and mental health issues, the following standards would assist in improving health outcomes for all people with disabilities: • Accessible services – not just physical access but administrative access (i.e. how appointments are made and followed up) • A safe environment • Feeling respected as an individual • Having one's privacy and confidentiality respected • Good communication – appropriate signposting, literature and written communication and complaints procedures • Good personal communication – using aids and supports as appropriate; having things explained in a way that is understood • Being listened to and having one's opinions sought and respected • High quality, evidence-based clinical care.

Organisation level	Organisation name	Policy name	Policy date	Reference to autism	Reference to disability	Relevant information
State	Victoria Office for Disability	Victoria Autism Plan	2019	✓	×	• Commitment for increasing understanding of health and well-being needs, including mental health needs, for autistic Victorians • Develop an autism workforce capability framework, outlining the understanding and skills required to meet the needs of people on the autism spectrum across key workforces, including health, mental health, public transport, justice, housing, family and community services • Better access to timely diagnosis • Through the Child Clinical Specialist Initiative in all child and adolescent mental health services, continue to improve leadership and responsiveness in engaging, assessing and treating children aged up to 12 years old with severe challenging behaviours, including those on the autism spectrum • Autistic people may face barriers accessing health and mental health services due to environments interacting with sensory sensitivities and communication styles. There is a need for stronger collaboration between services and greater understanding of autism among health (including mental health and allied health) professionals. There is also a significant need for work to ensure that autistic people's encounters with health services do not direct them to unsuitable care options and do not use health resources and programs to address underlying issues such as behaviours of concern • Consider approaches to strengthen the capability of clinical adult mental health services to recognise, assess and respond appropriately to autistic adults • Build autism competency across workforces through Department of Health and Human Services policies and guidelines to skill health and mental health workforces to respond positively to autistic Victorians • LGBTI+ autistic people should be able to draw on sage and appropriate services to meet their health, well-being and education needs • Promoting positive student well-being and mental health for autistic students is important to help them to feel less stressed and anxious, more positive about their abilities and future opportunities in education and employment, and more socially included • Funding mental health practitioners in every Victorian government secondary school campus by 2022.

Organisation level	Organisation name	Policy name	Policy date	Reference to autism	Reference to disability	Relevant information
Territory	Northern Territory Government: Territory families, housing and communities	Northern Territory Disability Strategy (2022-2023)	2022	×	✓	• Discrimination and low expectations cause people to feel bad about themselves and can damage mental health and well-being.
State	Western Australian Council of Social Service Inc	A Core Capability Framework: For working with people with intellectual disability and co-occurring mental health conditions	n/a	✓	✓	• Evidence that people on the autism spectrum, or other cognitive impairments, are also more at risk of developing mental health issues • Rights: People with intellectual disability, including those with a co-occurring mental health issue, and their families, carers and guardians have the right to have access to social, cultural and economic environments in relation to health and well-being • Inclusion: Required processes and structures are put in place to support access to services and the right to participate in community life by people with intellectual disability and co-occurring mental health issues • Holistic approach: People with intellectual disability and co-occurring mental health issues should be part of a person-centred approach to ensure they are supported to make choices and are in control of their care • Recovery oriented practice: People with intellectual disability and co-occurring mental health issues are supported to take responsibility for their lives respecting their experiences, expertise and strengths • Evidence-based and quality services: Best possible outcomes are sought by keeping informed of best available evidence, regularly reviewing policy and practice against standards and current legislation, and participating in professional development.

Organisation level	Organisation name	Policy name	Policy date	Reference to autism	Reference to disability	Relevant information
State	Commissioner for Children and Young People, Western Australia	Speaking Out About Autism: The views of WA children and young people with autism	2020	✓	✗	• Mental health of children and young people on the autism spectrum requires close attention and they need to be adequately supported at all times to cultivate positive and enduring growth and well-being. Autistic children and their families need equitable access to information, advocacy and resources from pre-diagnosis and through all life stages. • Key theme is having access to health and mental health services that understand autism • Accessible information and practical support for children and young people and their families to link into health and mental health services in the community • Appropriate services with understanding, well-trained health and mental health professionals • Prioritised mental health support, including mechanisms that identify autistic children and young people experiencing mental health conditions (e.g., autism specific assessment).
State	Chief Psychiatrist of Western Australia	Chief Psychiatrist's Guidelines	2015	✗	✓	• At times the behaviour of a person with intellectual disability (ID) may be misinterpreted as indicating mental health problem and the clinician needs to ascertain the causes of the behaviour. Further information from a family member, carer, personal support person, guardian, or staff at the Disability Services Commission (DSC) may indicate that what is being observed in an exaggeration of the types of behaviour associated with the ID. DSC workers may at times be confused as to whether the behaviour indicates a mental health problem or the exacerbation of behavioural symptoms associated with ID and may quite reasonable request a mental health assessment. It should be understood that at times people with an ID may suffer from depression or psychosis (akin to dual disability) and require mental health intervention.
State	Government of South Australia: Well-being SA	Disability Access and Inclusion Plan (2020 – 2024)	2020	✓	✓	• Well-being SA promotes days/months of significance (e.g., autism awareness months; international days of people with disability) • Mental health problem viewed as a disability. People with such disability are included in co-design of health promotion activities and other related projects • Well-being SA promotes days/months of significance (e.g., autism awareness months; international days of people with disability).

Organisation level	Organisation name	Policy name	Policy date	Reference to autism	Reference to disability	Relevant information
State	Tasmanian Government	Tasmanian Government Submission: Select Committee on Autism inquiry	2020	✓	✕	• Tasmanian government recognised that for Tasmanians on the autism spectrum and their families, friends and carers, access to quality, timely, and appropriate supports across all key life-stages can make a positive difference to their everyday lives. Failure to provide such supports across mainstream services including education; justice; health; mental health; children and youth services and housing, has a significant economic cost, not just for Tasmanians on the autism spectrum but for Tasmania as a whole as it strives towards a fully inclusive society that values and respects all people with disability as equal and contributing members of the community.

Note. Ahpra: Australian Health Practitioner Regulation Agency.

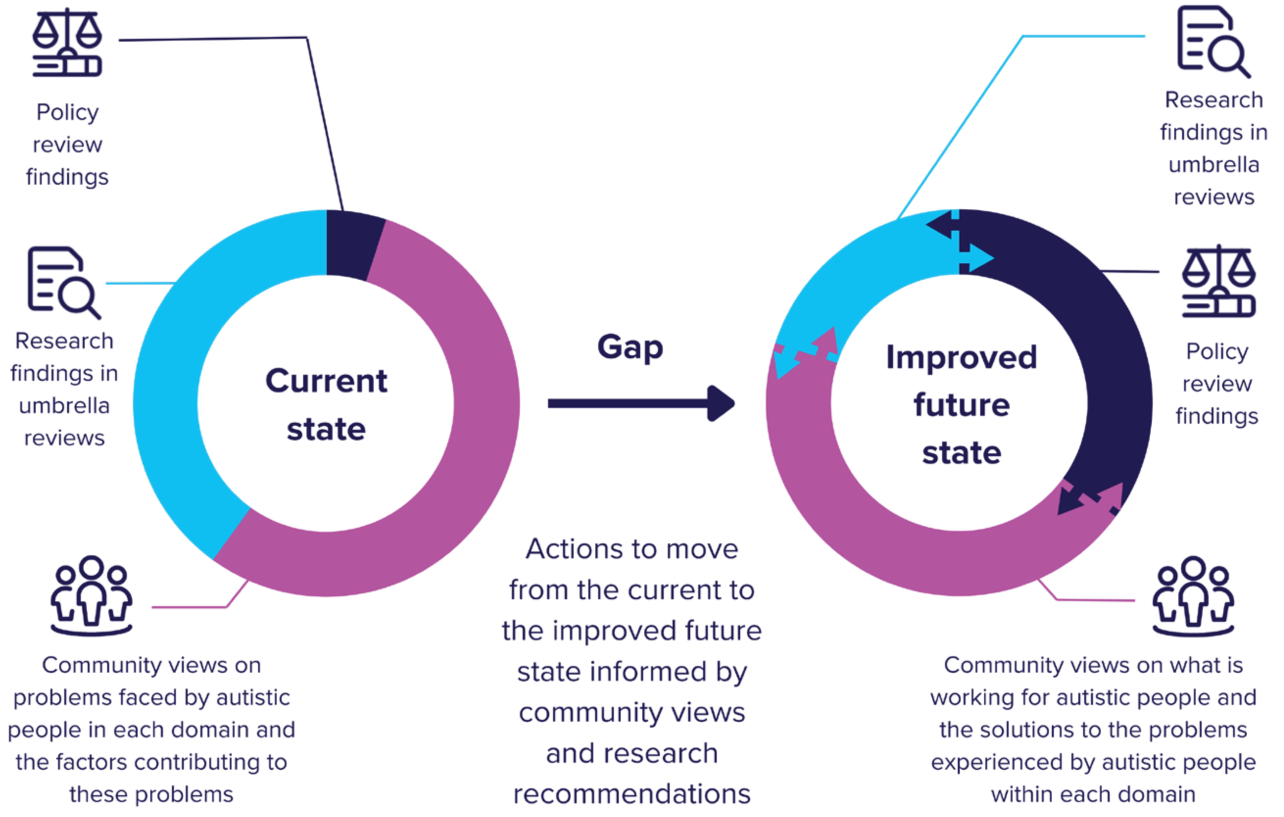
3.7.4 Additional information from literature reviews within other autism crc projects

Dr Kate Simpson from Griffith University has been leading Autism CRC Project “Quality of life and well-being of autistic individuals with complex support or communication needs”. This has involved a systematic review of all of the quality of life and well-being research regarding autistic individuals. Dr Simpson has provided a summary of the systematic review (please see Appendix J-5) which has been used to inform the gap analysis below.

3.7.5 Community views, research evidence, and policy/guideline alignment and gap analysis

As well as the research gaps identified as part of the research landscape mapping, the gap analysis (see Figure 8 for process) allows comparison of the *current state* (predominantly based upon the community views analysis but also some findings of the umbrella review and policy review) to an *improved future state* (based upon community views around what is working well, policy review, and some umbrella review findings).

Figure 8: Gap analysis: Current to improved future state



The gap analysis work for the mental health services section highlighted the following elements that need to be addressed in order to reduce the problems experienced by autistic people within this domain.

3.7.5.1 There is a need for autistic people to have timely and equitable access to affordable mental health services

Current state

The **community** views survey indicated that a common problem autistic people experience in relation to accessing mental health services is an insufficient availability or a lack of access to mental health services. Within the limited services that are available, there are long waiting lists (many services are reported to have closed waitlists), a lack of skilled therapists, and fees are too expensive. Whilst it is recognised that the insufficient availability of services may be impacting both autistic and non-autistic Australians, a lack of services and therapists is particularly impactful for the autistic community given the research showing that more autistic people (90.5%) than non-autistic people (12 to 16%) experience mental health challenges (see Salazar et al., 2015; doi.org/ 10.1007/s10803-015-2361-5). Additionally, the community survey also identified autism-specific barriers to accessing mental health services, including some people reporting a preference for non-face-to-face therapy, and people being denied access to a service because they are autistic, which further exacerbates the challenges in accessing services.

The **research** reviews confirm the perspectives within the community views, stating that many autistic people and family members of autistic people report being excluded from services due to their autism diagnosis, "falling between the cracks" of mental health and disability services. The reviews also document that long waiting lists and a lack of spaces in mental health services prevent autistic people from accessing services. The research within the reviews further concludes that many mental health practitioners do not feel confident in supporting the needs of autistic people, which may be a contributing factor to autistic people being denied access by services. Additionally, non-Australian research shows that some autistic children, particularly those from racial or ethnic minority groups, are less likely to be referred for mental health support.

Improved future state

Multiple policies within the **policy** review state that individuals in mental health services cannot be discriminated against because of their disability or diagnosis. The Royal Australian and New Zealand College of Psychiatrists position statements on addressing the mental health needs of autistic people (2022) indicate the need for an inclusive approach to mental health services to support equitable access and to equip "mainstream" services to meet the needs of all autistic people. Their position statement on addressing the mental health needs of people with intellectual disability (2022) also states that "mainstream" mental health services must be accessible to people with an intellectual disability (a co-occurring condition for a proportion of autistic people). Whilst comments in the **community** views survey recognised that NDIS funding has been beneficial for accessing mental health supports, respondents indicated that affordable mental healthcare and increased, easier to access funding for mental health supports would assist in reducing the challenges that autistic people face when trying to access mental health services.

Steps that can be taken to move from the current to the improved future state include:

- More training places for mental health professionals (including neurodivergent mental health professionals) with an interest or focus on autism and neurodiversity to increase workforce availability
- Training and professional development to increase mental health professionals' knowledge

- and competence to support autistic individuals (discussed further below)
- Collection and evaluation of data on Australian autistic individuals' service use and unmet needs, explored by intersectionality, to identify those who may be at increased risk of not accessing mental health services. This knowledge could be used to facilitate the co-development of resources to support any such group to access services, including information on the services that are available, how to access these services, and who can/how to access funding for mental health supports
- Government and/or professional bodies providing guidance on inclusive practice and how to ensure professionals practise within their competency without discrimination or denying people access to services based on their neurotype
- Co-designed autism-informed pathways within "mainstream" mental health services, akin to the PEACE pathway within the National Health Service (NHS) eating disorder service. This offers autism-informed therapies and supports within a standard ("mainstream") service
- Co-designed digital mental health supports for the autistic community. These could aim to prevent the development of mental health conditions (accessed proactively) and/or prevent further development of mental health conditions (e.g., which could be accessed while on waiting lists or trying to find a therapist).

3.7.5.2 There is a need to improve the level of autism knowledge and understanding of professionals working in mental health services, and for wider access to professionals providing neurodiversity affirming approaches.

Current state

Almost one in four people who completed the mental health section of the **community** views survey highlighted that mental health professionals' lack of knowledge of autism (or broader neurodiversity), its presentation, and its impact across the lifespan as a problem for autistic people when using, or trying to access mental health services. Respondents also highlighted that the misdiagnosis of autism as a mental health problem, along with mental health professionals' lack of knowledge of conditions that co-occur with autism, as additional problems that autistic people experience when using or trying to access mental health services.

The **research** landscape mapping results align with the community views. This highlighted that one of the most common barriers for autistic people accessing mental health services was the practitioner/professionals' lack of autism knowledge. Many professionals who support autistic people with their mental health have limited knowledge of autism, with one study reporting that some professionals get their knowledge of autism through personal connections or the media, rather than through training. There was limited Australia-specific research and no research within the reviews evaluated knowledge of mental health conditions in autistic people.

Improved future state

The **community** views survey highlighted that mental health services work well for autistic people when therapists are knowledgeable and/or experienced in autism. Aligning with this, the most frequently suggested solution to the problems autistic people face within mental health services (within the community views survey) was increasing the autism knowledge of professionals within mental health services through training.

Described in the policy review, multiple policy documents, including the Royal Australian and New Zealand College of Psychiatrists position statement “Addressing the mental health needs of autistic people” (2022) and the Victorian Autism Plan, indicate the need to educate and train health care providers in the mental health needs of autistic people. However, none of the other policies reviewed suggested or mandated autism training for professionals providing mental health services.

Steps that can be taken to move from the current to the improved future state include:

- Co-creation of a core capabilities framework for mental health professionals supporting autistic people (e.g., see the UK’s Core Capabilities Framework for Supporting Autistic People commissioned by Health Education England). This could inform training such as those described below
- Co-creation of evidence-based autism-specific training that is relevant and accessible to professionals providing mental health services. The effectiveness of this training could be supported by relevant federal and state policymakers suggesting or mandating completion of such training within policy. This could include training during initial courses as well as being included within annual professional development training offerings
- Co-development of specialised training for professionals whose role would benefit from more specific knowledge of autism, such as those supporting autistic people with more complex communication or support needs (e.g., see the National Health Service Oliver McGowan Mandatory Training on Learning Disability and Autism).

3.7.5.3 There is need for mental health services that provide accommodations and supports to enable autistic people to access their services

Current state

The **community** views survey highlighted that sessions and strategies offered by mental health professionals were not tailored to autistic people. This includes a lack of accommodations for autistic people’s communication, language, and communication styles or preferences. Of note, this was reported by 10% of autistic people but by only 3% of mental health professionals. As with other domains, the community views survey suggested many potential reasons for this, including a lack of autism knowledge, a lack of training, a lack of funding, and/or resource- and time-constraints of those working in mental health services.

The **research** review identified that many autistic people feel that mainstream mental health services are unlikely to meet their needs. Practitioners not adapting practices or supports to autistic clients was identified as a barrier to autistic people accessing mental health services. The reviews also concluded that mental health practitioners need to adapt their approaches to support autistic clients, but due to a lack of evidence and training, any adaptations or accommodations may be inconsistent and ad hoc.

Additionally, the **community** views survey highlighted that autistic people have problems accessing mental health services due to processes and systems, including challenges navigating systems and having to book appointments by telephone. The **research** reviews align with this, with barriers to accessing mental health supports including unclear referral access or pathways.

The **policy** review highlighted that telehealth arrangements are now being permanently supported. However, the **research** reviews show that little is known about feasibility, acceptability, and efficacy of telehealth and digital health supports to support the mental health of autistic people.

Improved future state

The **policy** review highlights that the specific mental health needs of autistic people should be considered in services, systems, and practices (The Royal Australian and New Zealand College of Psychiatrists position statements, 2022). The NDIS consultation paper on Interventions for children on the autism spectrum (2021) states that information should be presented in appropriate language or formats and the Ahpra Code of Conduct (2022) states that professionals should provide information in a way that the [autistic person] can understand. There is also a future commitment to deliver a pilot of specialised digital services “for people with complex mental health needs, including intellectual disability and autism” within the Australian Government response to the Select Committee on Autism (report): Services, support and life outcomes for autistic Australians.

The **community** views identified that mental health services work well for autistic people when there is support from family, friends, and the autistic/neurodivergent community. There was also recognition of the importance of safe, trusting therapist-client relationships, and of therapists who have good therapeutic skills (e.g., flexible, compassionate). The survey also highlighted that mental health services work well for autistic people when professionals offer a range of supports or therapies to promote well-being in autistic people, and when neurodiversity affirming or strengths-based approaches are available.

Steps that can be taken to move from the current to the improved future state include:

- Co-development of guidelines or recommendations of accommodations that mental health practitioners should offer to autistic people before, during, and after accessing mental health services. The guidelines or recommendations need a pathway to dissemination so that the information is provided to all practitioners which enables the supports or accommodations to be available and offered across a range of mental health service settings
- Co-development of resources, supports, and models of service for autistic people to help enhance their understanding of mental health and mental health services which can be accessed prior to (and while) accessing mental health services. Given that the community shared how important their support network can be when accessing mental health services, this may also include resources for members of the support network
- Additional evidence and research on effective strategies to support the mental health of autistic people. In order to support the broad range of communication preferences of autistic people, this evidence should go beyond face-to-face therapies to also consider digital resources, digital therapies, or less formal supports (e.g., online chat functions) co-developed with autistic people, for autistic people. Data on “what works” may also require collaboration with therapists working in clinical practice to identify new practices or approaches being used (e.g., neurodiversity affirming practices) and co-designing methods of evaluation of such practices.

3.7.5.4 There is a need to understand more about why autistic people experience elevated mental health problems and what can be done, outside of therapy, to reduce this risk

Current state

The **research** highlights that autistic people access mental health services more often than non-autistic people; this is not just limited to therapy. American data also show that psychiatry-related emergency department visits are nine times higher for autistic than for non-autistic children.

Policies recognise that specific intersectionalities and particular environments may lead to autistic people being more likely to develop mental health problems, but there is at present insufficient longitudinal research on the mental health trajectories of autistic people to identify autism-specific risk factors for developing mental health challenges. The **research** is not sufficiently developed to inform services on the environmental factors, including societal attitudes or acceptance of autism, which lead to or help prevent mental health problems in autistic people.

Improved future state

Policies state the need for mental health professionals to meet the recommendations of providing "the best mental healthcare to autistic people experiencing barriers to mental healthcare" and "maximising the well-being of individuals, families, groups, communities, and society". The **community** views consistently highlight the need for more services, more therapists, and more funding so as to ensure there are sufficient services to support the mental health needs of autistic people in Australia.

Steps that can be taken to move from the current to the improved future state include:

- Longitudinal co-developed research on the mental health trajectories of autistic people to identify autism-specific risk factors for developing mental health challenges. This should include environmental factors, including societal attitudes or acceptance of autism, which lead or help to prevent mental health problems in autistic people
- Co-development and evaluation of community-based initiatives to enhance public knowledge and acceptance of autism, which in turn lead to less negative experiences (e.g., bullying) which impact autistic people's mental health. This might include initiatives in schools, workplaces, and community groups, or through supporting accurate representation of autism within media. Any such initiative should cover the diversity of the autistic community by (for example) including autistic people from the LGBTQIA+ and culturally and linguistically diverse communities.

3.8 Physical health services

3.8.1 The "1,000 Insights" community views survey

A total of 606 respondents answered at least one of the questions on physical health services. This included 253 autistic people, 382 families or carers of autistic people, and 159 medical professionals and allied health professionals. The 10 most frequently reported responses (where applicable) are reported within this section.

The tables for each question describe the response categories (with example participant responses) in order from the most frequently reported to the least frequently reported. For each category, percentages are provided to indicate the proportion of a respondent group whose response reflected the specific category. These groups are: (a) the entire sample (i.e., everyone), (b) autistic people, (c) family members/caregivers of autistic people, (d) medical or allied health professionals, and (e) all respondents who are not represented in one of these groups.

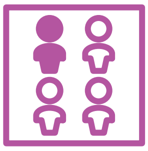
3.8.1.1 Problems experienced by autistic people when using, or trying to access, physical health services

A total of 606 respondents opted to answer this question on using, or trying to access, physical health services. This included 253 autistic people and 382 family members or carers of autistic people. The problems experienced were coded into 16 categories, which fall under the following six broad areas:

- Physical healthcare professionals' autism knowledge, skills, and practice
- Logistics and process of accessing services
- The physical environment of healthcare settings
- Communication between autistic people and those working in physical health services
- Cost and finance
- Fear and lack of trust when accessing services.

Table 47 ranks the 10 most commonly reported problems that autistic people experience in relation to accessing physical health services. The data are ranked from most frequently reported to least frequently reported problems across all respondents. The right-hand columns reports the proportion of specific respondent groups that identified this as a problem. Note that respondents often identified within multiple groups (e.g., autistic and a parent/caregiver of an autistic child), so the total of the subgroups will exceed the total number of all respondents.

Of note is that these data show that approximately:



Almost 1 in 4 respondents highlight a problem with the level of knowledge of autism of people (providers and non-providers) working in the physical health services.

Nearly 1 in 4 respondents highlight a problem with long waiting lists to access physical health services.

Almost 1 in 5 respondents highlight that health professionals are reluctant to adapt practices or provide accommodations/supports for autistic individuals or to see autistic clients.

Table 47: 10 most frequently reported problems experienced by autistic people in relation to physical health services

Rank	Problems experienced by autistic people in relation to physical health services and sample quotes from responses	Direct insight	Respondents who stated this as a problem				
			All respondents *N* = 606	Autistic people n = 253	Family member or caregiver of autistic people n = 382	Medical professionals and allied health professionals n = 159	Other respondent groups* n = 260
1	**Staff in healthcare settings (providers and administrative staff) have a poor understanding or knowledge of autism, how it presents in different people or contexts, and how it impacts the experience of healthcare settings** (e.g., outdated knowledge of autism; lack of knowledge of how autism impacts the experience of healthcare settings)	*"There is no indication at any GP or Health Care service that I have seen that they either specialise in or are experienced and trained to help autistic people. GP's and other health professionals do not know how to deal with autistic people."* (ID 915)	23%	23%	24%	29%	21%
2	**Long waiting lists to access physical health services** (e.g., long waiting time to access diagnostic, generalised, and specialised services)	*"Appointment waitlists are getting so long that by the time we get in, the problem is too far gone, already fixed, or we just don't want to go anymore because they don't care about us so why should we?"* (ID 153) *"There is nothing available in the regions. Everything is booked out for 12+ months."* (ID 570)	23%	13%	26%	25%	20%
3	**Health professionals' reluctance to adapt practices or provide accommodations/ supports for autistic individuals** (e.g., inflexibility, one-size-fits-all, lack of neurodiversity-affirming care)	*"Hospitals do not accommodate for the needs of people with autism. Quote from a hospital employee which identifies as disability friendly and has a disability liaison officer, 'they just have to suck it up'."* (ID 1172)	19%	17%	23%	15%	17%

Rank	Problems experienced by autistic people in relation to physical health services and sample quotes from responses	Direct insight	Respondents who stated this as a problem				
			All respondents *N* = 606	Autistic people n = 253	Family member or caregiver of autistic people n = 382	Medical professionals and allied health professionals n = 159	Other respondent groups* n = 260
4	**The sensory elements of physical health services or settings (including waiting rooms and emergency departments) are not supportive for autistic people, sometimes leading to sensory overwhelm** (e.g., crowded, bright and noisy waiting rooms)	*"Attending doctors' appointments is difficult. Waiting rooms are a sensory nightmare. [We are] often left waiting for a long time for appointments in waiting rooms then my daughter is over stimulated by the time her appointment is due to start, leading to erratic behaviour and meltdowns."* (ID 30) *"Hospitals are sensory nightmares. I went through chemotherapy for a year in sensory agony and no-one thought to turn off the fluorescent lights."* (ID 1163)	19%	19%	21%	21%	22%
5	**Physical healthcare providers dismissing or not believing the reports of autistic people or their family members (including not believing a person is autistic)** (e.g., dismissing symptoms or requests)	*"They don't listen when we speak. If we say we are hurting, they think we are lying."* (ID 935) *"My diagnosis of autism is commonly ignored, minimised or dismissed. I am then either judged as a liar, fraud or a difficult patient or I get spoken to as if I have intellectual disability as well."* (ID 1436)	16%	26%	15%	14%	17%
6	**Differences or difficulties with communication, including autistic people experiencing challenges with describing their experiences, having to frequently repeat information to providers, and physical health providers not presenting information in a way that is accessible to autistic people**	*"They are worried about having to talk about their feelings. This is hard to articulate."* (ID 255)	16%	17%	16%	12%	15%

Rank	Problems experienced by autistic people in relation to physical health services and sample quotes from responses	Direct insight	Respondents who stated this as a problem				
			All respondents *N* = 606	Autistic people n = 253	Family member or caregiver of autistic people n = 382	Medical professionals and allied health professionals n = 159	Other respondent groups* n = 260
7	**Lack of health professionals and services, and disparity based on location (i.e., regional and rural)** (e.g., limited number of allied health and medical professionals; no services for particular age group/gender)	*“Not enough psychologists/Speech Pathologists/OT to assess for ASD. Not enough psychologists/Speech Pathologists/OT to treat/manage social skills, sensory overwhelm and anxiety for those with ASD.”* (ID 477)	14%	8%	14%	17%	17%
8	**Services are too expensive to access**	*“It literally costs thousands every year. Even the reports to access the NDIS cost us over $10K combined (2 children). How do poor families access NDIS reports and ongoing medical care? I’m guessing many just miss out.”* (ID 1112)	15%	13%	14%	9%	13%
9	**Difficulties with the process to access and physically attend health services** (e.g., organising and understanding forms, service availability/options, paperwork and appointments; transport)	*“The amount of paperwork and hoops that the autistic person needs to successfully navigate in order to get help discourages people from trying.”* (ID 195)	12%	12%	10%	13%	15%
10	**Adjustments or accommodations not offered, or system not taking into account needs or preferences of autistic people** (e.g., appointments or therapies not autism-friendly; options for appointments [telehealth or in person]; and the process of arranging appointments or communicating with staff outside of appointments)	*“Everything requires a phone call - that's just not accessible for most autistic or neurodivergent people.”* (ID 1494)	12%	15%	11%	11%	11%

Note. *all other groups that have not been identified separately

3.8.1.2 Factors causing the problems experienced by autistic people when accessing, or trying to access, physical health services

A total of 536 respondents opted to answer this question on using, or trying to access, physical health services. This included 216 autistic people and 340 family members or carers of autistic people. The factors that respondent felt were causing or leading to the problems experienced by autistic people when accessing physical health services were coded into 16 categories. These categories fell under nine broad areas:

- Education and training of healthcare professionals
- Healthcare professionals' factors including knowledge of autism and skills
- Cost and finance
- Availability of, and access to, physical healthcare services
- Healthcare professionals' approach and practice when working with autistic people
- Government decisions and policy
- Set up of physical healthcare services and systems within services
- Physical and sensory environment of physical healthcare settings
- Autistic characteristics or communication profile

Table 48 ranks the 10 most commonly reported factors that respondents felt were causing the problems that autistic people experience in relation to accessing physical health services reported above. The data are ranked from most frequently reported to least frequently reported problems across all respondents. The right-hand columns report the proportion of specific respondent groups that identified this as a problem.

Importantly, these data show that approximately:

1 in 4 respondents stated that the problems were due to insufficient training provided to healthcare providers or insufficient funding available to provide this training.

1 in 4 respondents reported that the problems were due to staff in healthcare settings having insufficient knowledge of autism.

Table 48: 10 most frequently reported factors causing the problems experienced by autistic people in relation to accessing physical health services

Rank	Factors causing the problems experienced by autistic people in relation to accessing physical health services and sample quotes from responses	Direct insight	Respondents who stated this as a problem				
			All respondents *N* = 536	Autistic people n = 216	Family member or caregiver of autistic people n = 340	Medical professionals and allied health professionals n = 143	Other respondent groups* n = 231
1	**Lack of funding for autism education, training, and upskilling of physical healthcare professionals** (e.g., lack of training within undergraduate and postgraduate level; insufficient ongoing professional development and autistic-led training)	*“There is also little to no training about Autistic people in most standard Health training. As an OT we did one lecture in one subject once. There are still lots of old myths/ stigma in the general medical and allied health fields.”* (ID 762)	26%	26%	25%	32%	28%
2	**Staff in healthcare settings (including administrative settings) have a lack of knowledge or understanding of autism/ neurodiversity, diversity of presentations, and how autism/neurodivergence may impact physical health needs or symptoms** (e.g., pain) (e.g., lack of understanding individual needs; lack of understanding of autism; outdated knowledge)	*“Their knowledge of autism is based on dated young male stereotypes from a particular part of the spectrum. Health care services know little current information about older, late diagnosed autistic women like me. They have no concept of the depth of trauma caused by being an undiagnosed autistic women living in a neurotypical world for 60 years and generally think I’m a sook and take none of my physical medical issues seriously.”* (ID 1436)	24%	32%	24%	20%	28%
3	**Lack of funding/resources and/or difficulty accessing these supports (including the high costs of healthcare)**	*“Less doctors are bulk-billing these days, so autistic (as well as neurotypical) people are not seeking medical help when they need it.”* (ID 1212)	23%	18%	24%	22%	25%

Rank	Factors causing the problems experienced by autistic people in relation to accessing physical health services and sample quotes from responses	Direct insight	Respondents who stated this as a problem				
			All respon-dents *N* = 536	Autistic people n = 216	Family member or caregiver of autistic people n = 340	Medical profession-als and allied health profession-als n = 143	Other respondent groups* n = 231
4	**Insufficient number of available healthcare professionals** (e.g., lack of professionals entering the field; lack of staff retention and incentives; a lack of university placements to train new professionals)	*"Not enough allied health professionals available to be responsive. Since the introduction of NDIS people with a plan expect/are entitled to regular allied health intervention"* (ID 702)	17%	10%	18%	15%	18%
5	**Healthcare professionals demonstrating a lack of understanding, empathy, patience, care, and acceptance for autistic people** (e.g., professionals showing discrimination and stereotyping of autism)	*"Egos - people just don't care, and don't [have] the time to understand, or WANT to get to the bottom of the issue, to actually then offer any real assistance."* (ID 147) *"Discrimination. You are treated like damaged goods. You are considered not worth saving. Even told you are the responsibility of DHHS [Department of Health and Human Services]. You are particularly devalued if you are autistic, nonverbal and have cognitive delays."* (ID 878)	10%	13%	12%	7%	10%
6	**Neurotypical/majority needs prioritised, ableism, and lack of neurodiversity-affirming practice**	*"Because people expect everyone to look around and behave like everyone else... ASD are not typical and for the majority of lazy humans makes them too much effort. It is easy when everyone is the same."* (ID 469)	10%	13%	11%	8%	11%

Rank	Factors causing the problems experienced by autistic people in relation to accessing physical health services and sample quotes from responses	Direct insight	Respondents who stated this as a problem				
			All respondents *N* = 536	Autistic people n = 216	Family member or caregiver of autistic people n = 340	Medical professionals and allied health professionals n = 143	Other respondent groups* n = 231
7	**Lack of government support and guidance** (e.g., a lack of autism-specific research; lack of guidelines/policy; increased red tape and bureaucracy)	*"Stronger rules, regulations and ethics needs to be implemented to eradicate the way funding is brutally misappropriated by physicians and service providers."* (ID 515)	10%	10%	8%	11%	10%
8	**A system with overwhelmed and overworked staff, time pressures, and insufficient resources** (e.g., being rushed; no time for extra accommodations)	*"Clinical staff are too busy and the health system overloaded to meet the sometimes complex health needs of an autistic person."* (ID 859)	9%	7%	9%	8%	7%
9	**Demand for health system exceeds supply, including increase in the prevalence of autism diagnoses and an increase in healthcare needs**	*"The medical system is so swamped, sometimes I think they make it hard on purpose because they want fewer patients!"* (ID 479) *"The health system is under great strain and is not able to keep up with increasing physical health needs in GP clinics and hospitals, let alone other more specialist services"* (ID 1154)	8%	5%	9%	10%	8%
10	**Insufficient number of professionals or services with an interest/expertise in autism** (e.g., a lack of autistic professionals or those with lived experience; a lack of specialists in rural areas)	*"A number of graduate therapists are working for NDIS service providers with people who require skill[ed] professionals but they are not adequately experienced or trained which is a disadvantage to the Autistic person."* (ID 1006)	8%	6%	7%	8%	7%

Note. *all other groups that have not been identified separately

3.8.1.3 Factors that could prevent or reduce the problems experienced by autistic people when accessing, or trying to access, physical health services

A total of 515 respondents opted to answer this question on using, or trying to access, physical health services. This included 216 autistic people and 340 family members or carers of autistic people. The factors that respondents identified as preventing or reducing the problems experienced by autistic people when accessing physical health services were coded into 13 categories. These categories fall under the following seven broad areas:

- Education and training of healthcare providers to enhance knowledge of autism and skills for supporting autistic people
- Availability of, and access to, physical healthcare services
- Cost and finance
- Government decisions and policy
- Communication needs, preferences, and options
- Physical and sensory environment of physical healthcare settings
- Set up of physical healthcare services and systems within services.

Table 49 ranks the 10 most commonly reported factors that respondents indicated could prevent or reduce the problems that autistic people experience in relation to accessing physical health services reported above. The data are ranked from most frequently reported to least frequently reported problems across all respondents. The right-hand columns report the proportion of specific respondent groups that identified this as a problem.

Importantly, these data show that there was a clear, predominant factor highlighted by respondents:

2 out of every 5 respondents identified training in autism as a factor that could prevent or reduce the problems experienced by autistic people when accessing physical health services.

Table 49: 10 most frequently reported factors that could prevent or reduce the problems experienced by autistic people in relation to accessing physical health services

Rank	Factors that could prevent or reduce the problems experienced by autistic people in relation to accessing physical health services and sample quotes from responses	Direct insight	Respondents who stated this as a problem				
			All respondents *N* = 515	Autistic people n = 216	Family member or caregiver of autistic people n = 340	Medical professionals and allied health professionals n = 142	Other respondent groups* n = 230
1	**Increase (access to) education, training, and upskilling programs for healthcare professionals and administrative staff about autism, characteristics, and health impacts** (e.g., mandatory onboarding; autistic informed/delivered training; and university level training)	*"There needs to be greater education about Autism for everyone working in physical healthcare services settings, and this education needs to be designed or co-designed with Autistic people."* (ID 290)	45%	51%	43%	49%	47%
2	**Increase the number of healthcare professionals and health services available** (e.g., incentives to increase rural/regional service; broadening scope of practice for health professionals)	*"Train more doctors. Make it easier to transition to medicine later in life (e.g., scientists with PhD/pharmacists/vets could do a specialised MD training to build up the workforce."* (ID 578) *"Incentivising healthcare professions such as speech and occupational therapy."* (ID 1128)	21%	13%	22%	22%	23%
3	**Increase funding/resources and/or affordability of health services across the lifespan** (e.g., increasing access to funding; increasing bulk-billing services; reviewing funding systems such as NDIS)	*"We need funding for medical expenses. NDIS won't cover my medical conditions, even though they are known to be linked to my neurodivergence. I am not a list of diagnoses with symptoms that can be easily categorised, I am a whole person and everything interconnects."* (ID 70) *"Flexibility in the Medicare funding system so that autistic patients had the capacity to access health services in the manner most suited to their needs."* (ID 1149)	19%	17%	20%	18%	18%

Rank	Factors that could prevent or reduce the problems experienced by autistic people in relation to accessing physical health services and sample quotes from responses	Direct insight	Respondents who stated this as a problem				
			All respondents *N* = 515	Autistic people n = 216	Family member or caregiver of autistic people n = 340	Medical professionals and allied health professionals n = 142	Other respondent groups* n = 230
4	**Government reform, support, and guidance** (e.g., investment in research and services; guidelines, policy and regulations)	*"Inclusion of autism in policy, guidelines and pathways so that autism is considered at all levels of health service system."* (ID 1068) *"Looking at how policy and practice is not meshing and figuring out to streamline this more effectively, so it meets the needs of autistic individuals more effectively."* (ID 1463)	14%	14%	15%	13%	16%
5	**Increase access and use of physical healthcare services for autistic people and their families through the provision of accommodations, flexible access options, and supports** (e.g., increased flexibility; and increased access to supports)	*"An autistic person may appreciate being first to be seen (or sometimes last) - quieter, less people. [Having] a person at the front door who can assist others [with] directions, wheelchair, toy, drink etc. Someone who has a general understanding and helpful nature. This person might wear the same uniform, apron etc each day and is easy to identify."* (ID 452)	14%	14%	15%	10%	13%

Rank	Factors that could prevent or reduce the problems experienced by autistic people in relation to accessing physical health services and sample quotes from responses	Direct insight	Respondents who stated this as a problem				
			All respondents *N* = 515	Autistic people n = 216	Family member or caregiver of autistic people n = 340	Medical professionals and allied health professionals n = 142	Other respondent groups* n = 230
6	**Increase communication options to improve access to healthcare and access to information about healthcare** (e.g., web-based booking systems; text-based communication; opting in or out of telehealth [i.e., not assuming it is preferred or unpreferred])	*"It should be mandatory that Autistic patients be able to communicate with clinics and healthcare professionals in ways that they prefer. No-one would ask a blind person to read a form, after all."* (ID 290) *"Always have an online booking system for all health care services. This should be mandatory due to the fact some autistic people are not getting the health care they require or delaying accessing health care due to having to call for an appointment. In this technological age, this is a very easy solution to this problem."* (ID 873)	12%	17%	11%	13%	14%
7	**Enhance the therapeutic skills and awareness of healthcare professionals to support their work with autistic clients** (e.g., acceptance; showing empathy and patience)	*"More education and training on ND [neurodivergent]-affirming practices for all health professionals. The training needs to be affordable and accessible (e.g. online, self-paced as well as in-person) and is provided by health professionals who are ND."* (ID 385)	11%	12%	11%	11%	9%
8	**Create sensory-friendly physical health services or settings, including training on how overwhelming these environments can be and impact on their appointment** (e.g., create sensory-friendly waiting rooms and emergency departments)	*"More sensory friendly design choices (reduced lighting, quieter medical device notification systems) and accommodations (sensory friendly/quiet spaces…) considered for autistic patients."* (ID 1051)	9%	11%	9%	9%	11%

Rank	Factors that could prevent or reduce the problems experienced by autistic people in relation to accessing physical health services and sample quotes from responses	Direct insight	Respondents who stated this as a problem				
			All respon-dents *N* = 515	Autistic people n = 216	Family member or caregiver of autistic people n = 340	Medical profession-als and allied health profession-als n = 142	Other respondent groups* n = 230
9	**Actively employ, consult, and collaborate with neurodivergent practitioners, support workers, advocates, and those in leadership/decision-making roles** (e.g., consult with autistic people when designing or developing services; services actively employing neurodivergent practitioners, support workers, advocates)	*"Co-design with autistic people so needs are recognised and responded to in planning, implementation and delivery of services. Service reviews by autistic people, to guide change or recognise achievements."* (ID 677) *"Have more autistic doctors and nurses (medical professionals), and more autistic people include on the boards of hospitals and health services."* (ID 935)	8%	10%	8%	7%	10%
10	**Provide support and education to individuals and families to improve health experiences and access** (e.g., having support workers and advocates available; preparing autistic individuals for healthcare visits and procedures)	*"Where possible provide resources to prepare autistic people for procedures that may be overwhelming, such as blood collection, having a cannula put in, x-rays, CT, MRI, Mammograms etc. these resources could be written in consultation with autistic people."* (ID 1322)	8%	7%	8%	11%	9%

3.8.1.4 Factors that are working well, or have worked well, for autistic people in relation to physical health services

A total of 390 respondents opted to answer this question on using, or trying to access, physical health services. This included 161 autistic people and 257 family members or carers of autistic people. The factors that, when available, are reported to be working well, or have worked well, for autistic people in relation to accessing physical health services were coded into seven categories, which fall under seven broad areas:

- Nothing
- When health providers have knowledge of autism, related skills, and approaches to support working with autistic people
- When services are affordable (including Medicare and NDIS plans)
- When there is sufficient availability of, and access to, physical healthcare services
- When communication needs, preferences, and options are considered
- When the physical and sensory environment of physical healthcare settings is supportive of autistic people
- When there is increased access to comprehensive diagnosis and subsequent information to inform support.

Table 50 ranks the 10 most commonly reported factors that respondents reported to be working well, or have worked well, for autistic people in relation to accessing physical health services. The data are ranked from most frequently reported to least frequently reported problems across all respondents. The right-hand columns state what proportion of specific respondent groups reported this as a problem.

Importantly, these data show that approximately:

1 in 5 respondents did not feel that anything was working to support autistic people in accessing physical health services.

1 in 5 stated that when they do find the right physical health provider (who was often described as knowledgeable about autism, understanding, caring, patient, and/or non-judgemental), physical health services work well.

Table 50: 10 most frequently reported factors that are working well, or have worked well, in relation to autistic people accessing physical health services

Rank	What is working well, or has worked well, in relation to autistic people accessing physical health services and sample quotes from responses	Direct insight	Respondents who stated this as a problem				
			All respon-dents *N* = 390	Autistic people n = 161	Family member or caregiver of autistic people n = 257	Medical profession-als and allied health profession-als n = 105	Other respondent groups* n = 166
1	**Nothing/not a lot**	*"Nothing. Everything is designed to be difficult and you give up before you achieve what you set out to most of the time."* (ID 88) *"Nothing about the current system is working well. Nothing at all."* (ID 318)	22%	28%	22%	17%	24%
2	**When you find the right physical health provider for you, who was often described as knowledgeable about autism, understanding, caring, patient, and non-judgemental**	*"It's luck of the draw. Every now and then I come across someone who is gentle, understanding and genuinely wants to know my needs or my children's needs."* (ID 1081) *"I once had a nurse get angry at me for having a meltdown within hours after the birth of my baby! But … one nurse pulled me aside to tell me she understands, her nephew is autistic. This helped. People in the industry expressing their understanding from a personal perspective (in an appropriate and professional way!) works wonders to help me feel safe and supported."* (ID 1251)	18%	21%	20%	10%	18%
3	**When NDIS plans and funding are approved for health supports** (e.g., helpful NDIS coordinators can improve access to services; reduces financial burden on families)	*"NDIS has been helpful to support access to allied health services for my son."* (ID 384)	14%	9%	12%	19%	13%

Rank	What is working well, or has worked well, in relation to autistic people accessing physical health services and sample quotes from responses	Direct insight	Respondents who stated this as a problem				
			All respondents *N* = 390	Autistic people n = 161	Family member or caregiver of autistic people n = 257	Medical professionals and allied health professionals n = 105	Other respondent groups* n = 166
4	**When healthcare providers proactively ask about and provide alternative/flexible access, accommodations, and/or support for autistic individuals** (e.g., longer appointments; more flexibility with appointments; support people attending; home visits)	*"Being allowed advocates with them even as adults [and] longer consultation times awareness and acceptance."* (ID 773) *"I have only had one positive experience and the hospital worked with us and allowed the assistance dog into pre-op as well."* (ID 1061)	13%	9%	16%	13%	16%
5	**When supports are provided that prepare autistic individuals for accessing healthcare services or initiatives/supports that help access to health services** (e.g., preparation resources for autistic individuals; access to support workers; educated carers/families; supports for families)	*"Visiting the dentist often for very short appointments to get better at opening the mouth for viewing and touching the teeth."* (ID 942) *"Support workers funded through the NDIS to assist with access, physical access, and mental preparation and capacity building for the appointment."* (ID 998)	10%	8%	11%	9%	11%

Rank	What is working well, or has worked well, in relation to autistic people accessing physical health services and sample quotes from responses	Direct insight	Respondents who stated this as a problem				
			All respondents	Autistic people	Family member or caregiver of autistic people	Medical professionals and allied health professionals	Other respondent groups*
			N = 390	n = 161	n = 257	n = 105	n = 166
6	**When there are increased communication options to improve access to, and information about, healthcare** (e.g., web-based booking systems; option of telehealth; non-verbal communication options)	*“Telehealth appointments meant I was able to speak to a GP and turn my life around.”* (ID 154) *“I have had the option at a doctors of online booking with a comment section so that I could put in the reason that I was making the appointment. It was really helpful because it meant that when I got there the doctor already had the reason for my visit in front of them. I didn't have to try and remember all the details and then get them across while I was stressed and overwhelmed.”* (ID 323)	10%	12%	10%	10%	12%
7	**Healthcare providers having an awareness and knowledge of autism, the characteristics of autism (including sensory needs), and different presentations (including the presentation of autism in women or girls)**	*“There are more practitioners now who understand autism and women. I had to join a long waiting list, but I've found a psychologist and a GP who are great.”* (ID 291) *“Many autistic people have found a space free from judgement where they can unmask and work through their needs, values, cognitions and behaviour with a skilled practitioner.”* (ID 808)	9%	6%	9%	10%	11%
8	**When there is increased access to autism-informed health professionals and services** (e.g., autistic-led services; services that have expertise in autism)	*“Having dedicated autism services, like the dental clinic at Queen Elizabeth II Hospital in Brisbane. Clinicians in such services consistently work within the autism context and such services develop better processes for providing tailored health care for Autistic people.”* (ID 1362)	8%	8%	7%	11%	8%

Rank	What is working well, or has worked well, in relation to autistic people accessing physical health services and sample quotes from responses	Direct insight	Respondents who stated this as a problem				
			All respon-dents *N* = 390	Autistic people n = 161	Family member or caregiver of autistic people n = 257	Medical profession-als and allied health profession-als n = 105	Other respondent groups* n = 166
9	**When there is continuity of care and continuity of information across providers** (e.g., collaborative health teams; building relationships; individual care plans; accessible health information; health passports)	*"When medical professionals are well informed about an Autistic person's needs e.g. with written information, there is often increased choices that enable a greater sense of control and predictability and procedures are less traumatic."* (ID 354)	7%	6%	7%	9%	7%
10	**When providers ask questions and listen to autistic people and/or their family members, and include autistic individuals and their families in healthcare decisions**	*"When people have listened and you are treated with respect… When you are asked "How does that look like for you[?]"… Working together, and realising that if things aren't working out then you need to change approach, not just withdraw service."* (ID 495) *"An A&E [Accident and Emergency] doctor who spoke directly to my daughter. He explained what he wanted to do e.g. check [heart] rate, asked permission before using stethoscope. He described what was involved in inserting a cannula and why he wanted to do it, asked permission and allowed her to feel each implement before he used it. My daughter is 19 and this was the first positive interaction she has ever had with a health professional. He was kind yet matter of fact without being condescending. She left feeling heard and empowered."* (ID 1550)	7%	8%	9%	5%	7%

3.8.2 Umbrella review

An umbrella review is a form of research that brings together the findings of all existing reviews (systematic and scoping) that report on a specific topic. The focus of this review is on the physical health service itself (e.g., providers, delivery method), rather than on specific treatments offered when an autistic person accesses physical healthcare. As diagnosis and early supports or interventions are covered in previous sections and reviews, they were not included in this review.

The terms used for the searches and the number of articles identified, screened, and included are provided in Appendix K-1 and Appendix K-2. The final umbrella review reports on 34 systematic reviews, four of which were led by Australian authors. Almost all (*k* = 30; 88%) of the systematic reviews were written in the last five years. The 34 systematic reviews collectively report on 520 individual studies.

The information and findings from the included reviews are summarised in the subsections below. When reporting on the number of people or participants in the review, this will be represented as *n* = [number of participants]. When reporting on the number of reviews that considered a topic, this will be represented as *k* = [number of reviews].

3.8.2.1 Participants within included reviews

In total, the reviews included 391,830,472 participants, with sample size for individual reviews ranging from 1 to 36, of these 870,844 (0.22%) eere reported to be autistic. Only three systematic reviews provided information on the gender of autistic participants. Most of the autistic participants in these three reviews were male (average = 66.03%) and ranged in age from 1 to 65 years.

3.8.2.2 Quality of included reviews

The quality of the included systematic reviews was assessed using the JBI Critical Appraisal Tool for Systematic Reviews. This tool assesses the methodological quality of a systematic review. The maximum score is 33, which indicates a very high-quality systematic review. The average quality score for the 33 included systematic reviews was 25 (75.76%), with the quality score ranging from 17 to 32.

3.8.2.3 Topics of included reviews

The 34 reviews identified in the area of autism and physical health services can be summarised across six key topics. Of note is that these topics traverse the broad range of physical health settings, including primary care, hospitals, emergency departments, maternity services, and dental settings. The key topics identified were barriers and facilitators to accessing physical health services (k = 11 reviews); the experiences of autistic people and their supporters when accessing physical healthcare (k = 6); physical health practitioners: autism training, knowledge, and experience (k = 15); autistic people's use of, and predictors of use of, physical health services (k = 12); and communication and collaboration (k = 8) and technology and telehealth/telemedicine in physical health services for autistic people (k = 2). The key findings for each topic are discussed in Table 51.

3.8.2.4 Research gaps

The 34 reviews identified a number of research gaps, which are combined with research gaps identified by the authors of this report and summarised in Table 51.

The barriers to healthcare for Australian autistic individuals have not yet been documented. Research addressing this gap should ensure sufficient sample sizes and recruitment methods to answer some of the critical questions about unmet needs by intersectionality as well as specific healthcare setting. Such work could also investigate any association between unmet healthcare need and health outcomes.

Given the importance of communication and collaboration, autism-specific healthcare resources (purpose designed for the Australian healthcare setting) could be co-designed and their impact on accessing healthcare evaluated. This could include an autism-specific healthcare kit, which supports autistic people to prepare for appointments and monitor their health outside of healthcare appointments.

Autistic people and their family members feel that physical health care professionals lack knowledge of autism, and ways to tailor their approach to support autistic people. Physical healthcare staff also report a lack of knowledge on autism and scores on autism knowledge questionnaires confirm this. This highlights the need for research to address this issue through co-developed and co-delivered training, the impact of which should be assessed through subjective and objective methods.

Table 51: Umbrella review findings for physical health services

Topic	Number of reviews on topic; citations	Key findings	Key research gaps identified
Barriers and facilitators to accessing physical healthcare services	*k* = 11 AlHumaid (2022) Calleja et al. (2020) Erwin (2022) Mason et al. (2019) McBain et al. (2020) McLean et al. (2020) Samuel et al. (2022) Strauss et al. (2019) Walsh et al. (2020) Williamson et al. (2017) Wilson & Petersen (2018)	• Autistic people and their family members report more problems in accessing physical healthcare than individuals with other neurodevelopmental conditions or non-autistic individuals • Barriers exist across the system which result in autistic people and their family members delaying appointments or opting out of proactive/preventative procedures. Frequently reported barriers include: o Differences or challenges with communication, including challenges with describing pain or symptoms and with processing speed o Inflexibility of provider or procedures o Inconsistency of provider and their level of autism knowledge o Lack of collaboration between providers o Noisy, bright, and unpredictable environments o Waiting times and waiting areas o Complexity of healthcare system, including scheduling and following through with different appointments and procedures o Organisational challenges (remembering appointments, taking medicines) o Costs, including funding or insurance coverage o Past negative experiences with healthcare providers or concerns about stigma o Feeling that one's expertise about self or child was ignored. • Specific procedures were frequently reported as challenging and often avoided. These include physical examinations, procedures involving needles (including blood tests), and blood pressure measurement • Facilitators to accessing healthcare include: – Staff knowledge and accommodations for autism – Consistency of staff – Time to build a strong, positive relationship – Collaborative approach with both the autistic person and their parents/supporters – Clear, slow-paced communication with visual back-up – Financial assistance (US studies; Medicaid).	• What autistic young people identify as barriers to specific procedures or healthcare settings • Barriers to healthcare experienced by autistic adults with sufficient samples to explore barriers by patient factors (e.g., age, gender and ethnicity) and specific healthcare settings • Intervention mapping exercise to identify pathways to reducing both broad and situation-specific barriers • Autistic people's recommendations for adaptations to healthcare settings (virtual, or based on walk-through) • Co-development of interventions to reduce barriers to healthcare for autistic people; these may be patient (e.g., toolkit), provider, or organisational focused or may use technology (e.g., virtual reality, 360 walk throughs) to support the autistic person in advance of their healthcare appointment • Whether there is any association between barriers to healthcare and healthcare outcomes in autistic people • Acceptability and feasibility of autism-specific health check with associated resources to support access • Co-development and evaluation of training of all staff in healthcare settings which incorporates information on both the barriers and facilitators to autistic people accessing healthcare (see training section below)

Topic	Number of reviews on topic; citations	Key findings	Key research gaps identified
The experiences of autistic people and their supporters when accessing physical healthcare	*k* = 6 Boshoff et al. (2021) Erwin (2022) Koski et al. (2016) Sadatsafavi et al. (2022) Wilson & Petersen (2018) Williamson et al. (2017)	• Some autistic people are hesitant to disclose their diagnosis of autism due to fears of discrimination or provider misconceptions of autism. Parents of autistic children report feeling judged by professionals. • Autistic people and parents of autistic children feel rushed during healthcare appointments and feel they do not have enough time to explain their concerns to healthcare providers • The "invisible" nature of autism means that many healthcare providers may not modify their approach to support autistic patients • Parents of autistic children are less satisfied with their physical healthcare encounters than are parents of children with other neurodevelopmental conditions • Healthcare environments can be overwhelming sensory experiences. The impact of these environments increases with longer waiting periods. • To allow quality care and engagement, healthcare procedures and encounters need to be adapted to accommodate the sensory and cognitive profiles commonly experienced by autistic individuals. Appointments and procedures may also need to take longer to accommodate for needs • Tools to collect information on autistic patients' communication preferences, behaviours, sensory profiles, interests, and reinforcers have been developed and assessed in UK and US healthcare settings; none are reported for Australian settings. Patients with care plans based on this information report better experiences in hospital	• The experiences of young autistic people who have accessed physical healthcare • Co-development and evaluation of a "healthcare kit" which includes items to support healthcare appointments (e.g., visual schedules, sensory-regulation items) • Review of current instruments to describe autistic patients' profiles and preferences leading to co-development and evaluation of a brief profile relevant to the Australian healthcare system

Topic	Number of reviews on topic; citations	Key findings	Key research gaps identified
Physical healthcare providers: Autism training, knowledge, and experience	*k* = 15 AlHumaid (2022) Boshoff et al. (2021) Burke et al. (2019) Clarke & Fund (2022) Cooke et al. (2020) Coughlan et al. (2020) Corden et al. (2022) Erwin (2022) Kouo & Kouo (2021) McCormack et al. (2020) Morris et al. (2019) Morris et al. (2021) Strauss et al. (2019) Walsh et al. (2021) Wilson & Petersen (2018)	• Autistic people and parents of autistic children feel that healthcare providers do not have sufficient knowledge of autism. As a result, many healthcare providers do not understand how the needs of autistic patients differ and do not adjust their approach or procedures to support their autistic patient • Healthcare providers' limited knowledge of autism was reported across multiple reviews. One review notes that the majority (69%) of studies report healthcare provider participants to have "inadequate knowledge" of autism. Knowledge was higher in those who had a personal connection to autism. Knowledge was also higher in paediatricians as compared to general practitioners or adult healthcare providers • Healthcare providers describe the complexity of providing care to autistic people (predominantly children). Many healthcare providers are aware that autistic people may require supports beyond those typically provided • Healthcare providers only report moderate levels of self-efficacy in working with autistic people. They report not feeling confident in knowing how to support the needs of autistic patients. Many will refer patients on to other specialists whom they view as being more experienced or having more resources to support autistic patients • Healthcare providers report limited access to autism-specific training. For those who have received training, the outcome is positive; trials of autism-specific training of healthcare providers result in increased positive outcomes in 80% of studies. Many of these positive outcomes remain present after 6 months	• How young autistic people feel about their physical healthcare providers' level of autism knowledge. • Australian healthcare providers' knowledge of autism using a measure of autism co-developed with the autistic community (to ensure it assesses what autistic people want their healthcare practitioners to know) • Australian healthcare providers' knowledge and experience of autistic patients of differing ages, with differing profiles, or with different intersectional identities • How Australian healthcare providers would like to receive training on autism and how this can be delivered to all geographical regions of Australia • Co-development and evaluation of co-delivered training on autism for healthcare providers and all healthcare staff (e.g., receptionists, administrators), evaluated with patient simulation and other objective data assessments • The effectiveness of embedding autism-related content (potentially through patient narratives) and competency-based assessments across initial training of healthcare providers

Topic	Number of reviews on topic; citations	Key findings	Key research gaps identified
Autistic people's use of, and predictors of the use of, physical health services	*k* = 12 Bishop-Fitzpatrick & Kind (2017) Boshoff et al. (2021) Burke et al. (2019) Calleja et al. (2020) Casagrande & Ingersoll (2021) Dallman et al. (2021) Gilmore et al. (2022) Lytle et al. (2018) Martin et al. (2022) McBain et al. (2020) Smith et al. (2020) Tregnago & Cheak-Zamora (2012)	• Autistic people have higher rates of physical health problems, yet almost 25% of autistic children have at least one unmet health need (US data). This is significantly higher than children with other neurodevelopmental conditions • Autistic children access 2-13 times more non-psychiatric outpatient appointments, 2-4 more non-psychiatric inpatient appointments, and visit the emergency department 1.1-4 times more than individuals with other neurodevelopmental conditions or non-autistic individuals. This is predominantly based on US data. No equivalent Australian data were reported • Studies reporting on US autistic adults' use of healthcare services report mixed results. Most report no significant difference from non-autistic people for emergency department use. Autistic adults have lower rates of preventative physical health examinations (e.g., cervical cancer screenings) but higher rates of hospitalisations and primary care appointments than non-autistic individuals. No equivalent Australian data were reported • Autistic individuals in the US have healthcare costs that are 2-4 times higher than those with other neurodevelopmental conditions and up to 9 times higher than non-autistic individuals. Individuals with co-occurring conditions, and those with more autism characteristics, have higher healthcare costs • Some autistic children are less likely to receive physical health services or are less likely to be satisfied with the services received. This is particularly apparent for those from racial or ethnic minority groups. Older autistic children, those with lower scores on measures of autism characteristics, and those from lower income families are also less likely to receive allied health services • Some interventions to empower parents of autistic people to navigate and access healthcare show improvements in parent knowledge but few result in higher levels of service access	• Australia-specific data on healthcare access, healthcare costs, and unmet health needs for autistic people, as compared to non-autistic people, explored in relation to age, ethnicity, cultural background, socioeconomic status, and gender. Such studies should include data on all aspects of healthcare including primary care, preventative healthcare, emergency department visits, hospitalisations, acute healthcare, and dental healthcare as well as allied health. Consideration of quality as well as quantity of healthcare accessed • Whether geographical location (metro vs. rural/remote) impacts on healthcare access for autistic individuals • Co-developed empowerment programs that work in partnership with healthcare providers • Co-development of an autism-specific model of health disparity (cf. National Institute of Health) which explores the environmental, sociocultural, behavioural, and biological determinants of health disparities in autistic individuals. This may help to identify the role of healthcare service access in healthcare outcomes of autistic people across the lifespan

Topic	Number of reviews on topic; citations	Key findings	Key research gaps identified
Communication and collaboration	*k* = 8 Boshoff et al. (2021) Erwin (2022) Koski et al. (2016) Kouo & Kouo (2021) Morris et al. (2019) Samuel et al. (2022) Strauss et al. (2019) Wilson & Petersen (2018)	• Collaborative partnerships are described as an “integral aspect” of healthcare for autistic people • Autistic people of all ages and abilities can have challenges communicating their pain or describing symptoms. They may prefer to use written or alternative ways to communicate these experiences. Challenges in (verbally) communicating can be exacerbated in times of high anxiety or sensory overload • Autistic people and parents of autistic children need clear, concrete explanations of options and procedures which allow enough time for processing and opportunities for questions. Having information provided in written form minimises the risk of information not being heard or being forgotten • Generic information on healthcare procedures is less likely to meet the needs of autistic people than non-autistic people • Parents of autistic children do not always feel that healthcare providers listen to them or acknowledge their role as an expert in their child • Parents of autistic children feel frustrated at the lack of communication between healthcare providers. Gaps in parent-provider communication lead to lower feelings of satisfaction with healthcare • Misunderstandings in communication may arise from healthcare staff misinterpreting the characteristics of autism • Healthcare providers report challenges in communicating with parents of autistic children when the parents are experiencing stress	• Co-development of guidelines for shared-decision making and person-centred medical care for autistic people • The utility of co-developed autism-specific information resources for healthcare (e.g., on pregnancy, sexual education/health) • Training for healthcare providers (see training section) to reduce misinterpretation or miscommunications
Technology and telehealth/ telemedicine	*k* = 2 Knutsen et al. (2016) Sutherland et al. (2018)	• Parents of autistic children generally report equal levels of satisfaction with telemedicine and face-to-face input from healthcare providers • Autistic individuals report high levels of satisfaction with telehealth methods • Telemedicine has adequate feasibility for delivering healthcare information or coaching to parents of autistic children	• The views and experiences of young autistic children who receive healthcare through telehealth • Barriers and facilitators of autistic people engaging in telehealth approaches for physical healthcare • Physical health outcomes (rather than acceptability) following telehealth • The acceptability and feasibility of patient- and problem-centred telehealth models, where patients access a telehealth appointment with a specialist in their diagnosis or presenting issue, rather than necessarily one in their local area

Note: Co-development in this context means with the autistic and autism community and with people who will receive the training (i.e., healthcare staff)

3.8.3 Policy and guideline review

To capture a broad range of policies and guidelines at a national and/or state/territory-based level, a series of internet searches were conducted (see Appendix K-4 for more information). The policies and guidelines identified covered 15 relevant sectors within the Australian health system, including: general practice; medical specialist services; nursing and midwifery; allied health; Medicare; Primary Health Networks; health promotion, health protection and disease prevention; aged care services; dental and oral health; Aboriginal and Torres Strait Islander health services; public hospitals; private health insurance; Veterans' health; medicines and medical devices; and the National Disability Insurance Scheme. Information within the identified policies relevant to autistic individuals or people with disability is summarised in Table 52.

The search identified 27 physical health service policies or guidelines. These policies and guidelines were all published or updated between 2016 and 2022, with 89% (n = 24) published or updated in the last 5 years (2018 to 2023). All 27 policies included provided some information relevant to individuals with disabilities; only three (11%) provided information directly relevant to autistic individuals. The policies summarised in Table 52 were distributed across national and state/territory levels with six from a national level, four from Australian Capital Territory, four from New South Wales, four from Victoria, three from Queensland, three from South Australia, two from Western Australia, one from Northern Territory and none from Tasmania. While additional policies were considered during this review (including those from Tasmania), only those that provided: a) information relevant to either autistic people or people with disability; or b) additional unique information over and above that already summarised in Table 52, were included.

Of note, there were 12 physical health sectors, for which policies or guidelines relevant to autism were not identified during the search process. These included: general practice; medical specialist services; allied health; Primary Health Networks; health promotion, health protection and disease prevention; aged care services; dental and oral health; Aboriginal and Torres Strait Islander health services; private health insurance; Veterans' health; medicines and medical devices; and the National Disability Insurance Scheme. This may indicate that autism-related policies or guidelines are not available for that sector/profession, they are available only for individuals working within the profession, or they are difficult to access. The latter suggests that people working in, or interested, in this sector or profession may have difficulty accessing information that may assist in supporting autistic people.

3.8.3.1 Policy and guidelines relevant to autistic people

The three documents that specifically discussed information pertinent to autistic individuals highlighted that:

- Autistic children can access allied health services nationally, with a relevant referral, through the Medicare Benefits Scheme. They are unable to claim for these services if already accessing these for a co-occurring disability
- In Queensland, it is recommended that autistic individuals' medical, behaviour, sensory and communication plans are considered when presenting with acute behavioural episodes in emergency departments. Collaboration with health professionals and care teams is recommended, particularly if information is unknown or treatment or transfer to another setting is required

- In the ACT Disability Strategy, specialist training of nurses and other carers is promoted to better support the sensory and other needs of autistic individuals receiving both hospital and home care.

3.8.3.2 Policy and guidelines relevant to people with disability

The 27 polices and/or guidelines that provided information pertinent to individuals with disabilities revealed that within physical health services:

- Individuals with disabilities have been identified as a vulnerable population, experiencing poorer health outcomes and access to health services than individuals without disabilities. Ensuring access to physical health services and safe and respectful experiences has therefore been prioritised for individuals with disabilities within many national and state/territory health policies. This is in line with national discrimination and disability legislation and health professional code of conducts
- Health professionals have a legal responsibility to provide a significant medical history regarding a person's disability
- Extra support may be required by individuals with disabilities to understand their diagnosis, management plans, transition of care processes and how to access services. This includes:
  - Developing and communicating relevant health information in ways that are appropriate for each individual. This is of particular importance to those who may be non-speaking, use alternative communication strategies, and/or have intellectual disabilities. Providing sufficient time, support, short and clear statements, and minimising medical jargon should be prioritised by health professionals to ensure that individuals with disabilities are able to understand and make informed choices about their health care
  - Coordinating and collaborating with care teams and support networks, particularly when an individual lives in supported accommodation or accesses multiple services
  - Providing educational resources and engagement opportunities to empower people with disability, including access to health promotion and prevention programs and strengthening links with NDIS support staff.
- Considering the physical environment around and within health facilities may overcome barriers to access for some individuals with disabilities.
- While access to safe medicines should not be impacted by location of care, including disability care settings, it is acknowledged that there are current accessibility challenges for individuals with disabilities around required medications, medicine reviews, labelling and information, and communication with health professionals
- Access to medical equipment loan schemes is dependent on the jurisdiction. For example, individuals with disabilities are not eligible to access the New South Wales assistive technology loan scheme, however, in the Northern Territory, the equivalent scheme is open to individuals with permanent or long-term disability
- It is important to include people with disability in the development of health policies and programs that impact them.

Table 52: Policy and guideline review findings for physical health services

Organisation level	Organisation name	Policy name	Policy date	Reference to autism	Reference to disability	Relevant information
National	Medical Board Ahpra	Good Medical Practice: A code of conduct for doctors in Australia	2020	×	✓	• Culturally safe and respectful practice requires genuine efforts to adapt your practice as needed, to respect diversity and avoid bias, discrimination, and racism. It also involves challenging assumptions that may be based on, for example, gender, disability, race, ethnicity, religion, sexuality, age, or political beliefs • No discrimination on the grounds of disability.
National	Palliative Care Australia	National Palliative Care Standards (5th Ed – 2018)	2018	×	✓	• Provision of palliative care for people who live in supported accommodation (e.g., disability residential services) is likely to require coordination of care between different services and different sectors including disability and health. For some people living with a disability, additional support may be required to assist them in understanding a diagnosis and prognosis, which can also complicate symptom management. Staff may also need to be aware of non-verbal or alternative communication strategies to assist them in the provision of care • Specific attention is paid to the needs of people who may be vulnerable or at risk, to support communication, goal setting and care planning. This includes, but is not limited to, people with intellectual disabilities • Clinicians should check that the child and their parents have been provided with sufficient support to make decisions. This includes support for children and parents who have communication difficulties, or decision-making difficulties associated with disability, mental illness or cognitive impairment.
National	Nursing and Midwifery Board Ahpra	Code of Conduct for Nurses and Midwives	2018	×	✓	• Adopt practices that respect diversity, avoid bias, discrimination and racism, and challenge belief based upon assumption (for example, based on gender, disability, race, ethnicity, religion, sexuality, age, or political beliefs) • Nurses must use expertise to protect and advance health and well-being of people with disabilities.

Organisation level	Organisation name	Policy name	Policy date	Reference to autism	Reference to disability	Relevant information
National	Australian Government Department of Health	Medicare Benefits Schedule Book	2020	✓	✓	• A consultant paediatrician or psychiatrist can refer a child on the autism spectrum or other pervasive development disorders (PDD) to eligible allied health professionals for treatment services • A child can access either the allied health services for autism/other PDD or for disability, but not both • If a child sees a consultant paediatrician or psychiatrist other than the one who put the treatment and management plan in place, the consultant paediatrician or psychiatrist who is seen subsequently can refer the child for any remaining allied health treatment services that are available to the child. Children with an existing treatment and management plan can be reviewed under attendance items for consultant psychiatrists and paediatricians. Where the patient presents with another morbidity in addition to autism or other PDD, item 132 can also be used for development of a treatment and management plan. However, the use of this item will not provide access to Medicare rebateable allied health services for treatment of autism or any other PDD • A person is considered to have an intellectual disability if they have significantly sub-average general intellectual functioning and would benefit from assistance with daily living activities. The health assessment provides a framework for medical practitioners to comprehensively assess the physical, psychological and social function of patients with intellectual disability and to identify any medical intervention and preventative health care required. The assessment must include: (a) dental health check; (b) aural examination; (c) ocular health; (d) nutritional statis and review of growth/development; (e) bowel and bladder function; (f) medications; (g) immunisation statis; (h) exercise opportunities; (i) support for activities of daily living; (j) need for breast examination; (k) dysphagia and gastro-oesophageal disease; (l) risk factors for osteoporosis; (m) seizure control if diagnosed with epilepsy; (n) thyroid disease; (o) aetiological diagnosis; (p) treatment for co-occurring mental health issues; (q) timing of puberty and management of sexual development and activity; (r) signs of physical, psychological, or sexual abuse.
National	Australian Government Department of Health	National Preventive Health Strategy 2021-2030	2021	×	✓	• People in lower socioeconomic groups are at greater risk of poor health, with higher rates of illness, disability and premature death • Health inequities are, in particular, experienced by certain groups within society, including people with disability • People with disability are considered a priority population.

Organisation level	Organisation name	Policy name	Policy date	Reference to autism	Reference to disability	Relevant information
National	Australian Government Department of Health and Aged Care	National Medicines Policy 2022	2022	×	✓	• Access is irrespective of diversity, background, age, disability, location, or personal circumstance • The way information is developed must be appropriate to each person's culture and language, health beliefs, accessibility, disability, and information needs • People living with disability may face specific challenges including accessing the required medicines formulations and medicine reviews, communicating with health professionals, and accessing easy to read written information about their medicines • The location of care delivery should not impact safe access to medicines, whether in different states and territories, in hospital or community health care settings or in environments such as disability care settings.
State	Queensland Primary Health Networks	Inquiry into Social Isolation and Loneliness in Queensland	2021	×	✓	• Queensland Primary Health Networks are all actively working on cross sector programs which work to address the social and emotional determinants of health in communities including people with a disability.
State	Queensland Health	Aboriginal and Torres Strait Island Mental Health Strategy 2016 to 2021	2016	×	✓	• Indigenous Queenslanders experience more ill-health and disability than non-indigenous Queenslanders • Aim to develop approach to working with a single care plan for people with mental illness that links mental health needs with any other community-based social and disability services they may require.
State	Queensland Health	Management of Patients with Acute Severe Behavioural Disturbance in Emergency Departments	2021	✓	✓	• Specific considerations should be made for patients with a disability such as those with intellectual disability or autism. If possible, seek advice from patient's treating paediatrician/psychiatrist or if transferring to another facility the accepting paediatrician or psychiatrist. Details should be sought on current medication plans, behaviour support plans, communication, plans/aides, and sensory considerations for the patients (particularly for those diagnosed with autism) • Use short clear statements which do not include medical jargon. The patient may not have the capacity to process information. For patients with a disability ensure communication aligns with the considerations in the patients' communication plan.

Organisation level	Organisation name	Policy name	Policy date	Reference to autism	Reference to disability	Relevant information
State	NSW Government	Clinical Principals for End of Life and Palliative Care (guidelines)	2021	×	✓	• Improves equitable access for priority and underserved populations, such as people with disabilities • The screening and identification process also recognises and identifies populations that face barriers in accessing and using services because of disability or communication difficulties.
State	NSW Government	Elective Surgery Access	2022	×	✓	• Treating doctor must provide significant medical history (including disability).
State	NSW Government	Emergency Department Patients Awaiting Care (policy)	2018	×	✓	• Communication should be via a range of methods that accounts for the patient and family/carers understanding of information, and any cultural, language, social, or disability requirements that are identified • When patients presenting to an Emergency Department are considered to be at risk, or who have a particular security need, a risk assessment to identify and address the identified security risks must be undertaken. These patients may include patients with development disability, and patients with mental illness or mental disorder.
State	NSW Government	Assistive Technology	2020	×	✓	• A person is ineligible for assistive technology through NSW Health if the assistive technology sought is required to support a disability.
State	ACT Government	ACT Drug Strategy Action Plan 2022-2026	2022	×	✓	• People with disability are more likely to use alcohol and illicit drugs than the general population but are less likely to access treatment services • People with disability are often exposed to unique stressors and obstacles to equal participation in society which can contribute to increased risk of harm from alcohol, tobacco and other drugs • It is important to include people with disability in development of policies and programs impacting them, and to balance harm reduction approaches with recognising and respecting the rights of people with disability • Establish a multidisciplinary service to support young people who have mental health needs co-occurring with trauma, disability and/or drug and alcohol use.

Organisation level	Organisation name	Policy name	Policy date	Reference to autism	Reference to disability	Relevant information
State	Canberra Health Services Policy	Elective Surgery Access	2021	✗	✓	• Healthcare facilities should consider the language and cultural needs of particular patient groups including individuals with disabilities. Mechanisms should be in place to align the information provided to patients with their capacity to understand, wherever possible.
State	Human Capital Alliance	Future Directions of Disability Health in the ACT: Phase one of the ACT disability health strategy project	2021	✓	✓	• Specialist training for nurses and other carers is stimulated, including learning how to support and care for people with intellectual disabilities who have for instance sensory impairments and/or autism • Key considerations for improving the health of people with disabilities include: (1) using person-centred care; (2) using a strengths-based social model of disability; (3) concept of reasonable adjustment embedded in national and ACT anti-discrimination legislation; (4) “universal design” of health services (including facilities, equipment, and processes) to improve access to care; (5) considering health care needs alongside social and cultural backgrounds, and/or additional health challenges; (6) people with disability are at high risk of adverse health outcomes; (7) “patient held” health information helps ensure safety and good health outcomes; (8) proactive and regular health assessment can improve health outcomes; (9) patient navigation support is effective in managing known risks; (10) capacity for effective reasonable adjustment relies on clear organisational process; (11) positive attitudes and behaviours of health care professionals; (12) training and development of health care providers supports them to become experienced and confident in dealing with people with disabilities and their support networks; (13) clearly established and monitored performance indicators as a driver of accountability and positive change; and (14) collection of relevant data is critical for quality assurance and quality improvement.
State	ACT Health	Health Canberra: ACT preventative health plan 2020-2025	2020	✗	✓	• Through the Healthy Canberra Plan continue to work in partnership with the ACT community to tailor responses that meet the needs of all population groups at all stages, including, people with a physical or intellectual disability.

Organisation level	Organisation name	Policy name	Policy date	Reference to autism	Reference to disability	Relevant information
State	Victoria Health	Victorian Cancer Plan 2020-2024: Improving cancer outcomes for all Victorians	2020	×	✓	• There are more than one million people with disability living in Victoria. The health status of people with disability is worse than for the general population in ways that are not always directly related to an individual's disabilities. Discrimination and a lack of inclusion have a negative effect on a person's health, both directly and indirectly • In Victoria, the priority under-screened groups include people with disabilities. Through the under-screened program, targeted initiatives to increasing screening include improving access to cancer screening for people with a disability.
State	Ambulance Victoria	Accessibility Action Plan 2020 - 2022	2020	×	✓	• Strategic priorities and accessibility action plan includes a co-design approach whereby they aim to establish and maintain mutually beneficial relationships with people with disability and their representatives to improve service delivery. This involves understanding the lived experience of disability, addressing assumptions, finding solutions, and achieving sustainable outcomes • Aim to (1) deliver educational campaigns, tools, and engagement platforms that empower people with disability to better understand and access Ambulance Victoria's services; (2) train and equip Ambulance Victoria staff with knowledge, skills and resources to better engage with people with disability, their carers and support networks; (3) improve access to buildings, facilities and ambulances for people with disability; (4) establish accessible methods to capture, monitor and respond to feedback, complaints and grievances from people with disability and their representatives.
State	Victoria State Government	Victorian Public Health and Well-being Plan 2019 - 2023	2019	×	✓	• When implementing action towards the priorities of the plan, consideration should be given to the needs of Victoria's diverse population, including people with disability.
State	Victoria State Government, Department of Health and Human Services	Victorian Aids and Equipment Program Guidelines	2020	×	✓	• Targets people who require assistive technology on a permanent or long-term basis for a health or ageing-related need. People with a disability who do not meet National Disability Insurance Scheme (NDIS) eligibility due to age, residency status or functional impairment level can also apply to the Victorian Aids and Equipment Program.

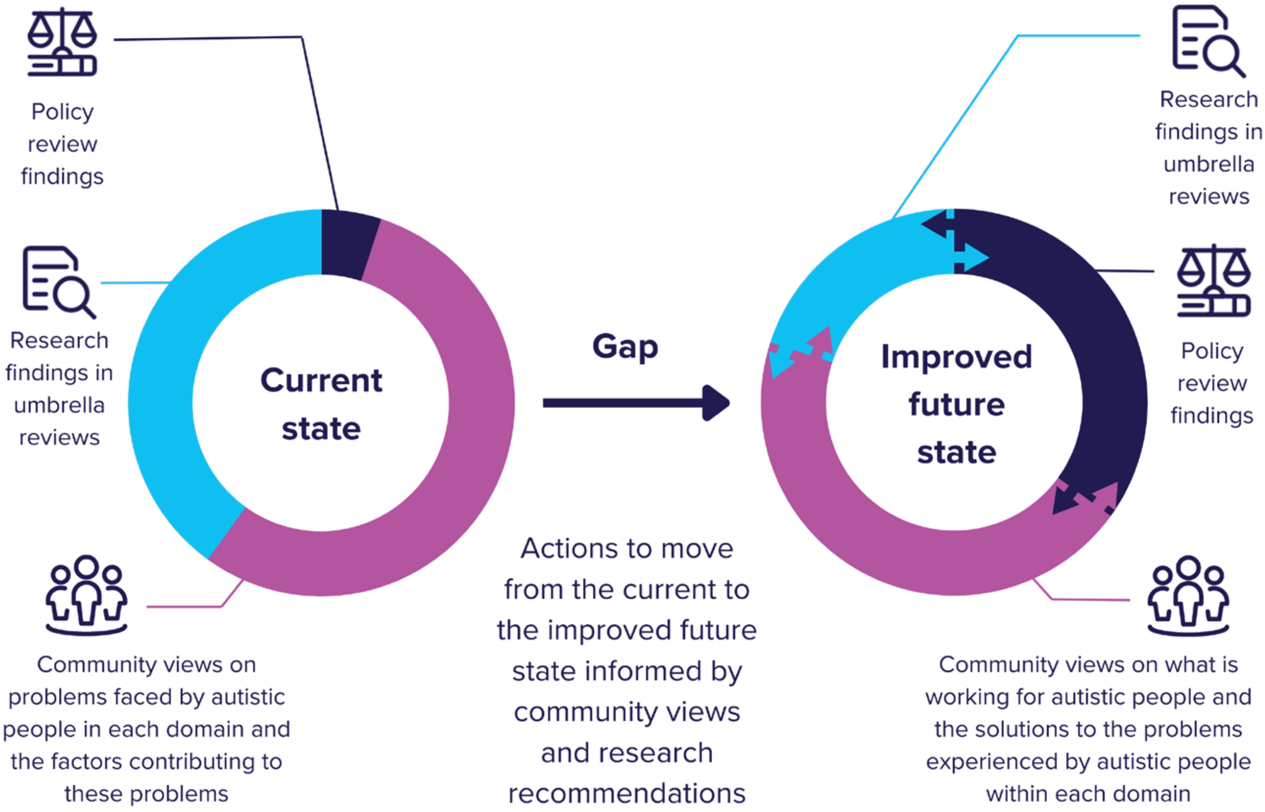
Organisation level	Organisation name	Policy name	Policy date	Reference to autism	Reference to disability	Relevant information
Territory	Northern Territory Government, NT Health	Territory Equipment Program (TEP) and the Seating Equipment and Technical Service (SEAT)	2022	×	✓	- TEP aims to provide prescribed items of assistive technology to assist eligible residents of the Northern Territory with a permanent or long-term disability, to enhance their safety and independence, and to assist them to live and participate in their community.
State	Government of Western Australia, Department of Health	Ambulance Services Western Australia: A framework for statewide ambulance service operations	2021	×	✓	- Ambulance services are delivered in a manner that is accessible to – and inclusive of – people with disability and that does not reinforce stereotypes.
State	Government of Western Australia, Department of Health	Western Australian Health Promotion Strategic Framework 2017-2021	2017	×	✓	- The main target groups for the WA HPSF include people with disabilities, and carers and families of people with sickness and disability - Targeted interventions: complement population approaches with targeted approaches that are inclusive of needs and issues of sub-populations at higher risk of overweight and obesity (e.g., people with disabilities) - Reduce barriers and increase opportunities for physical activity across all populations, including people living with disability.
State	Government of South Australia	South Australian Alcohol and Other Drug Strategy 2017-2021	2016	×	✓	- Ensure that services to address (1) alcohol problems; (2) illicit drug use; or (3) hazardous and harmful use of pharmaceutical drugs, meet the needs of people with a disability.
State	Government of South Australia, SA Health	Health and Well-being Strategy 2020 - 2025	2020	×	✓	- Provide better long-term care for people with a disability and improve links with the NDIS - People with disability, and their families and carers, often have poorer health outcomes. These groups are considered priority populations.

Organisation level	Organisation name	Policy name	Policy date	Reference to autism	Reference to disability	Relevant information
State	Government of South Australia	SA Health Regional Aged Care Strategy 2021 - 2025	2021	×	✓	• The strategy will consider other sectors that closely interface with aged care services (e.g., disability services).

3.8.4 Community views, research evidence, and policy/guideline alignment and gap analysis

As well as the research gaps identified as part of the research landscape mapping, the gap analysis (see Figure 9 for process) allows comparison of the *current state* (predominantly based upon the community views analysis but also some findings of the umbrella review and policy review) to an *improved future state* (based upon community views around what is working well, policy review, and some umbrella review findings).

Figure 9: Gap analysis: Current to improved future state



The gap analysis work for the physical health services section highlighted the following elements that need to be addressed in order to reduce the problems experienced by autistic people in relation to physical health services.

3.8.4.1 There is a need to improve the level of autism knowledge and understanding of professionals working in physical health services

Current state

Almost one in four people who completed the physical health section of the **community** views survey highlighted physical healthcare professionals' lack of knowledge of autism (or broader neurodivergence), its presentation, and its impact on the experience of healthcare for autistic people. Of note is that more medical professionals and allied health professionals reported this as an issue than did autistic people or family members.

The **research** landscape mapping results align with the community views. There were 15 systematic reviews on physical healthcare professionals' level of autism training, knowledge, and experience. These conclude that physical healthcare professionals have "inadequate" knowledge of autism and many lack confidence to treat autistic patients. This finding is also reported by research sharing the views of autistic people and parents of autistic children, who feel that healthcare professionals do not have sufficient knowledge of autism. The lack of professional knowledge of autism was also highlighted as one of the most common barriers for autistic people accessing physical health services. There was limited Australia-specific research and no research within the reviews which evaluated knowledge of physical health conditions in autistic people.

Improved future state

The **community** views survey highlighted that physical health services work well for autistic people when they find a physical healthcare professional who is knowledgeable and/or experienced in autism. Aligning with this, the most frequently suggested solution to the problems autistic people face in relation to physical health services (within the community views survey) was increasing the autism knowledge of professionals within physical health services through training; this was recommended by 45% of respondents.

The **policy** review highlighted that there is a recognised need for specialist training on how to support the needs of people with disabilities (e.g. Future Directions of Disability Health in the ACT, 2021, Ambulance Victoria Accessibility Action Plan, 2020). However, none of the other policies reviewed suggested or mandated autism training for professionals providing physical health services.

Steps that can be taken to move from the current to the improved future state include:

- Co-creation of a core capabilities framework for physical healthcare professionals supporting autistic people (e.g., see the UK's Core Capabilities Framework for Supporting Autistic People commissioned by Health Education England). This could inform training such as those described below
- Co-creation and co-delivery of evidence-based, autism-specific training that is relevant and accessible to anyone working in physical healthcare settings, not just healthcare professionals. The uptake (and therefore effectiveness) of this training could be supported by relevant federal and state policymakers suggesting or mandating completion of such training within policy. This could include training during onboarding, and for healthcare professionals, training embedded into initial courses as well as training that would be provided within annual professional development training offerings

- Co-development of specialised training for professionals whose role would benefit from more specific knowledge of autism, such as those supporting autistic people with more complex communication or support needs (e.g., see the National Health Service Oliver McGowan Mandatory Training on Learning Disability and Autism). This could go beyond knowledge to include simulated practice assessments.

3.8.4.2 There is a need for autistic people to have timely and equitable access to affordable physical health services

Current state

The **community** views survey indicated that a common problem autistic people experience in relation to accessing physical health services is long waiting lists, insufficient availability of services (especially outside of metropolitan areas), and services being too expensive to access. Whilst it is recognised that these issues may impact both autistic and non-autistic Australians, these issues may be particularly impactful for the autistic community as the **research** review showed that autistic people experience significantly poorer physical health than non-autistic people, and access physical health services more often than non-autistic people. Costs and waiting times were also highlighted in the research review as barriers for autistic people who need to access physical healthcare.

Improved future state

Policies recognise the health inequalities experienced by individuals with disabilities (National Preventative Health Strategy, 2021). They highlight the need to ensure people with a disability (which, within policy, would include autistic individuals) and their families can access physical health services, with some noting this as a priority area.

The **community** views survey highlights the need for more healthcare professionals, especially those in autism specialist roles or those who could form autism-focussed services, and increased funding for physical healthcare services. Ensuring that autism is considered and autistic people consulted in all aspects of healthcare related policy and processes, was also highlighted as a solution to the problems noted above.

Steps that can be taken to move from the current to the improved future state include:

- More training places for physical healthcare professionals (including neurodivergent physical healthcare professionals) with an interest or focus on autism and neurodivergence to increase workforce availability
- Collection and evaluation of data on Australian autistic individuals; service use and unmet physical healthcare needs, explored by intersectionality and co-occurring conditions, to identify those who may be at increased risk of not accessing services. This knowledge could be used to facilitate the co-development of resources to support any such group to access services, including information on the services that are available, how to access these services, and who can/how to access funding for physical health supports
- Community consultations on autism-specific health checks with associated resources to support access
- Autistic people to sit on advisory boards and boards of directors for hospitals or specific clinics.

3.8.4.3 There is a need for autistic people and their supporters to feel heard and believed by those in physical health services

Current state

The most frequently reported problem with physical health services reported by autistic people in the **community** views survey was that they are dismissed or not believed by physical healthcare professionals; this was reported by more than a quarter of the autistic people who completed this question on the survey. This included physical healthcare professionals questioning a person's autism diagnosis.

The **research** expands upon this by highlighting that some autistic people are hesitant to disclose their diagnosis of autism due to fears of discrimination or professional misconceptions of autism. Parents of autistic children also report feeling judged by professionals. Importantly, past negative experiences and the feeling that one's expertise (either about self or child) are dismissed were identified reasons that autistic people or their families delay appointments or opt out of proactive/preventative procedures.

Improved future state

Multiple policies, including the Ahpra Code of Conduct for Doctors and for Nurses and Midwives **policy,** state the need to respect diversity, avoid bias and discrimination, and challenge assumptions based on disability. The **community** views survey highlighted that physical healthcare works well for autistic people when the physical healthcare professional questions and listens to autistic people and/or their family, and includes the opinion of autistic people and/or their family in healthcare decision-making.

Steps that can be taken to move from the current to the improved future state include:

- In addition to the recommendations on autism training noted above, this calls for specific training on the presentation and support of healthcare issues experienced by autistic people. This should enhance professionals' understanding of health conditions in autistic people, allowing them to learn that whilst symptoms and presentations of health conditions may differ between autistic and non-autistic people, an autistic person's healthcare condition experience(s) are no less valid
- Guidelines and guidance around procedures that autistic people can follow should they need to change practitioner or seek a second opinion due to their symptoms being dismissed or disbelieved.

3.8.4.4 There is a need for physical health services that provide accommodations and supports to enable autistic people to access their services

Current state

Almost one in five respondents in the **community** views survey felt that physical healthcare professionals are reluctant to adapt practices or provide supports for autistic people. A further 16% also reported that they experienced significant challenges in communication during their physical healthcare appointments. Examples included autistic people finding it hard to express their experiences/symptoms, autistic people not being supported to use communication methods other than speech, and physical healthcare professionals not presenting information in a way that is accessible to autistic people.

The findings from **research** align with community views, with autistic people's differences or challenges with communication, including challenges with describing pain or symptoms and with processing speed, and inflexibility of professionals or procedures, being two of the most commonly reported barriers for autistic people when accessing physical healthcare settings. The research describing the experience of autistic people or their supporters suggests that they often feel rushed in appointments and like they do not have enough time to explain their concerns to their physical healthcare professionals. The research also shows that parents of autistic children are less satisfied with their physical healthcare encounters than are parents of children with other neurodevelopmental conditions. Communication and collaboration between healthcare professionals and autistic people or their supporters was discussed in eight systematic reviews. Autistic people and their supporters feel unheard or their expertise unvalued in appointments. Communication challenges are exacerbated during times of high anxiety or sensory overload. Healthcare professionals also find it challenging to communicate during these times.

Improved future state

The **policy** review highlights the importance of "adapting practice as needed" (Ahpra Good Medical Practice: A code of conduct for doctors in Australia, 2021). Policies also specifically highlight the need to communicate relevant health information in ways that are appropriate for each individual, which may require additional time, short and clear statements, and minimising medical jargon.

The **community** views survey identified that physical health services work well for autistic people when physical healthcare professionals proactively ask about, or provide, accommodations or supports for autistic individuals. Examples included longer appointment times and inviting support people to attend in advance. Having additional support before or during healthcare appointments (e.g., support worker visits, information on processes or procedures in advance) and allowing alternative modes of communication (including options for booking appointments online and having appointments online) were both identified as additional factors that can make physical healthcare services work well for autistic people.

Steps that can be taken to move from the current to the improved future state include:

- Co-development of guidelines or recommendations of accommodations that physical health practitioners should offer to autistic people before or during physical health services. The guidelines or recommendations need a pathway to dissemination so that the information is provided to all practitioners which enables the supports or accommodations to be available and offered across a range of physical health service settings (e.g., ambulance settings, dental settings)
- Clear guidance and skills-based training for healthcare professionals on communicating with patients through methods other than spoken communication, such as the communication boards developed for use in the Queensland Ambulance Service (see autismcrc.com.au/knowledge-centre/resource/emergency-communication-board). Once professionals feel competent, all patients could then receive advice in the appointment letter that they will be able to communicate through their preferred means, and a reminder to bring along any preferred communication support device, resources or communication partner to their appointment

- Consultation with the autistic and autism communities regarding a method of indicating on medical records that the patient identifies as autistic, so that supports or appointment times/durations can be proactively tailored if needed
- Co-developed autism-specific health education materials. These could include generic information on specific healthcare issues or procedures (including home-based screening procedures), or clinic-specific information such as appointment or service-specific information
- Co-development of an autism-specific healthcare access toolkit relevant to the Australian context (American example autismandhealth.org/).

3.8.4.5 There is a need for easy-to-access services with low-sensory environments

Current state

The sensory elements of the physical health settings were identified within the **community** views survey as a problem for autistic people accessing physical health services. Additionally, one in 10 people also report that autistic people experience problems with accessing and physically attending physical health services. This includes elements such as challenges with transport, organisation, completing or understanding forms, and knowing about service options or entitlements.

Research studies within the umbrella review identified bright, noisy, or unpredictable environments and experiences of waiting areas as physical barriers to healthcare for autistic people. Additionally, there were barriers relating to the complexity of healthcare system, including scheduling and following through with different appointments and procedures, and organisational challenges.

Improved future state

As noted previously, the **policy** review highlights the importance of "adapting practice as needed" (Ahpra Good Medical Practice: A code of conduct for doctors in Australia, 2021). However, the policy does not specifically go into detail about ensuring physical environments are accommodating or considerate to sensory needs. The **community** views survey suggested making sensory-considerate physical healthcare services and settings as a solution to the some of the problems autistic people face when trying to access physical healthcare settings. This included a recommendation that professionals receive training about the impact of sensory profiles on healthcare experiences. The community also suggested that resources or supports should be provided to autistic people and/or family members to improve their access to healthcare (e.g., support to make appointments, autism-specific information on how to access healthcare, etc.).

Steps that can be taken to move from the current to the improved future state include:

- Guidance for healthcare settings to conduct environmental audits including noise and light levels, and suggested accommodations/adjustments that can be made to adjust areas that may pose challenges for autistic people. As part of this audit, opportunities should be provided for autistic people accessing the setting to provide feedback on sensory supportive and non-supportive elements
- Co-produce resources to support autistic people to communicate their sensory and communication preferences prior to or within physical health services. Explicit invitation and permission (e.g., on appointment letter, posters in waiting rooms) for people to bring along sensory supports to use/wear before, during, or after appointments.

3.8.4.6 There is a need to understand more about why autistic people experience elevated physical health problems and what can be done, outside of healthcare settings, to reduce this risk

Current state

The **research** highlights that autistic people access more than double the number of physical healthcare appointments than non-autistic people. The broader research also highlights higher health problems and a reduced life expectancy for autistic people.

Policies recognise that individuals with disabilities have poorer health outcomes and access to health services than individuals without disabilities. The **research** is not sufficiently developed to inform services on the environmental factors which lead or help to prevent physical health problems in autistic people.

Improved future state

Policies specifically identify autistic individuals as a priority population for healthcare and highlight a need for improved equitable access for such populations.

Steps that can be taken to move from the current to the improved future state include:

- Longitudinal co-produced research on the physical health status and needs (met and unmet) of autistic people. This could then identify autism-specific risk factors for developing physical health challenges. This should be proactively designed to include those from intersectional or marginalised groups and with co-occurring conditions, as these may also be people who are at risk of not engaging with, or having unmet needs related to, physical healthcare services
- Co-development of an autism-specific model of health disparity (cf. National Institute of Health) which explores the environmental, sociocultural, behavioural, and biological determinants of health disparities in autistic individuals. This may help to identify the role of healthcare service access in healthcare outcomes
- Co-development and evaluation of community-based initiatives to understand and reduce the ongoing, significant chronic stress and/or trauma experienced by autistic people, which may be impacting autistic people's physical health. This might include initiatives in schools, workplaces, and community groups, or through supporting accurate representation of autism within media. Any such initiative should cover the diversity of the autistic community by (for example) including autistic people from the LGBTQIA+ and culturally and linguistically diverse communities.

4. Summary and conclusion

This comprehensive report combines the community views of over 1,000 community members, the findings of 185 systematic reviews (reporting on over 700 research studies and over 2,500,000 participants) and relevant content of 120 policy documents, to provide an understanding of the current landscape of eight service domains relevant to the lives of autistic people across Australia. As well as being reported upon individually, these three elements were used to conduct a gap analysis to compare the current state to an improved future state. Potential ways to move from the current to an improved future state were also suggested within each domain, leading to identified needs, i.e., areas for action and improvement which have the potential to be addressed within the National Autism Strategy and beyond.

4.1 Summary of identified needs across domains; areas for action or improvement

Whilst the report is presented by each specific domain, the gap analyses identified *needs*, or areas for action and improvement, that were present across multiple domains. Table 53 provides a summary of these areas across the eight domains. The table shows the pervasiveness of the issues and challenges experienced by autistic people in relation to accessing services or supports. In doing so, it highlights some clear paths on how to reduce these. The areas for action or improvement may be potential **priority areas** to be addressed within **the National Autism Strategy**.

Of note is that five areas for action and improvement were noted in at least half of the service domains. These were:

- There is a need to for **greater understanding of autism and its diversity.** This was the most frequently reported need across, and often within, each of the eight domains. A limited understanding of autism and its diversity was often identified as a problem experienced by autistic people, whereby professionals may have insufficient autism knowledge to effectively support autistic people. Across all domains an increased understanding of autism was seen as necessary to better understand the strengths and needs of autistic people, and how to tailor approaches when working with autistic people, reducing stigma and discrimination. Additionally, the need to improve the broader community understanding of autism was noted across multiple domains
- There is a need to **provide and/or ensure adjustments, accommodations, and supports** for autistic people. This was identified across five domains. This included autism specific or autism-tailored pathways within services. The community survey frequently highlighted that accommodations to support neurodiversity were often lacking, resulting in challenges in attending, engaging with and/or accessing services. Ensuring that autistic people are provided with appropriate adjustments and accommodations ensures that autistic people have the opportunity for equitable access to participate and thrive across settings including work, school, healthcare or other services, home, and the community
- There is a need for increased **timely and equitable access to services.** This was identified in six domains. The length of waitlists and difficulties in accessing services due to location (i.e., regional, rural, and remote) and/or an insufficient number of professionals were frequently identified as barriers to accessing services and supports for autistic people. This is particularly

impactful for the autistic community given research showing that more autistic people than non-autistic people experience mental health and physical health challenges. Increasing the number of professionals knowledgeable about autism would lead to better health and diagnostic services access for autistic people

- There is a need to ensure that **physical environments are sensory-considerate.** This was highlighted in four domains. Environments (e.g. schools, hospitals court rooms) that are not designed to be supportive of sensory processing differences can limit accessibility for autistic people. Proactively designing buildings and physical spaces to be inclusive for autistic people supports an equitable access to services
- There is a need to **reduce financial barriers.** This was identified in four domains. The often-prohibitive cost of services was associated with, for example, delays in receiving an autism diagnosis which in turn can prevent access to early intervention and support. These financial barriers were also identified as preventing or limiting access to health care. Reducing these financial barriers could support the quality of life and well-being of autistic people.

Table 53: Needs (i.e. areas for action and improvement) identified in the gap analysis across each of the eight domains

There is a need for...	n	Diagnosis	Early Intervention or Supports	Education	Employment	Housing and Independent Living	Justice System	Mental Health Services	Physical Health Service
Greater understanding about autism and its diversity within government, services, professionals, workplaces, and/or the community	8	✓	✓	✓	✓	✓	✓	✓	✓
Provision of adjustments, accommodations, and supports for autistic people to ensure equitable access, including through autism-tailored pathways	7		✓	✓	✓	✓	✓	✓	✓
Increased timely and equitable access (e.g., through more services, more providers, broader geographical access or locations)	6	✓	✓		✓	✓		✓	✓
Reduce sensory stimuli in **environments,** more **sensory-considerate** environments in services	4			✓		✓	✓		✓
Reduce financial barriers	4	✓	✓					✓	✓
More co-produced research to understand more about factors that contribute to autistic people needing to access this service	3						✓	✓	✓
More options and choice about the service or setting that will best support autistic people	3		✓	✓		✓			
More neurodiversity affirming approaches and understanding of autism and neurodiversity	3	✓		✓				✓	
A clear, consistent, and equitable approach to autism assessments	2	✓					✓		
Families of autistic children to be better supported, helping them better understand autism and provide optimal care to autistic children	1		✓						

The other areas for action and improvement were:

- The need to increase understanding about **factors that contribute to autistic people needing to access** specific services, which was identified in three domains. For some areas (e.g., justice system), autistic people are more likely than non-autistic people to access the service. By understanding the reasons for this, supports can be developed to reduce this risk
- The need to **provide choice for autistic people** was identified in three domains. Without sufficient options, it assumes a "one-size-fits-all" approach, which does not reflect the diversity of strengths, interests and challenges across and within autistic people. By providing multiple options, it ensures that autistic people and their supporters are able to select the option that is best for them and their particular needs, skills, and preferences. It also affirms autonomy and right to self-direction
- The need for **neurodiversity affirming approaches** and understanding of autism was highlighted in two domains. This approach acknowledges that the differences in how autistic people interact with the world should be embraced, rather than seen as something that needs to be changed or "fixed". This neurodiversity affirming approach is associated with a positive sense of self-identity and moves away from a deficit-view of autism (e.g., viewing these differences as "impairments").

While some areas were only identified in one service domains, they still provide useful direction for improvements given how the service domains are inherently interlinked (e.g., early diagnosis supports access to early intervention).

4.2 Limitations and considerations of the findings

Multiple domains highlighted that the participant groups in the available research do not represent the diversity of autistic people now recognised and embraced. Within research there is a clear under-representation of females or those who identify with non-binary gender (e.g., in Justice System research), those with specific co-occurring conditions such as intellectual disability, and an under-description of other intersectionalities such as race/ethnicity and cultural background. Therefore, where policy is able to draw upon research, it must do so with knowledge of the research limitations, and place a call to action for researchers to address these gaps with high-quality, co-designed participatory research. Additionally, the survey data has minimal participants from a number of intersectional groups who are frequently underrepresented in research (e.g. those who have co-occurring intellectual disability, identify as non-speaking, users of augmented and alternative communication, those who identify as First Nations or culturally and linguistically diverse, and those in out of home care). Further work is needed to learn from the experiences of individuals with these intersectional identities.

Whilst the umbrella research reviews allow for reporting on a wide range of articles within each domain area, they do not allow for the inclusion of the most recent research findings. However, it may be that even the most recent research is behind the community experiences and clinical practice; for example, on 27th June 2023, a Google Scholar search for term "neurodiversity affirming" identified only six published academic journal articles on the topic. When the same search was conducted in Google on the same date, it returned 143,000 hits for websites including this term. Stronger collaborations between the autistic community, researchers, policy makers and those working in the service domains is needed to ensure that the research is focussing upon what is needed for policy and what is relevant to current community experiences and clinical practice. The policy search, whilst systematic and in-depth, could not identify policies that are internal to services or organisations.

4.3 Conclusion

> *“Coming together is a beginning; keeping together is progress; working together is success.”*
>
> *– Edward Everett Hale*

The National Autism Strategy, alongside other government policy and government discussions around autism, has the potential to make real, positive change for autistic Australians. The community views survey, and the research reviews, highlight the significant problems that autistic people and their supporters face on a daily basis when trying to access services in Australia. The responses in the community survey highlight the distress and potentially even trauma that is often experienced by autistic people and their supporters due to these experiences. This needs to change to enable autistic people to participate in work, school, home, and community activities, and/or have equitable access to healthcare and to the justice services.

The gap analysis between the current experiences and the improved future state highlighted significant needs (i.e., areas for action and improvement). Many of these impact across multiple domains and therefore addressing these areas for improvement have the potential to redefine outcomes for autistic people across the lifespan. These should be driven by policy that will enable and facilitate change through government, systems, organisations and professionals. The latter include researchers, autistic-led organisations and supporters of autistic people.

In addition to informing the National Autism Strategy and informing positive change, the community views survey has provided a synthesis of experiences pre-National Autism Strategy. The National Autism Strategy will no doubt set a vision of improvements for autistic Australians into the future, and stipulate the outcomes they expect to change once the strategy is implemented. A repeat of this work, especially the community views survey, will allow for an evaluation of “real change” experienced post-strategy; only by doing this is it possible to quantify how successful the strategy has been in achieving its goals.

Whilst the community perspectives and research and policy reviews are reported in this document in individual and specific domains, none of these happen 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). Therefore, stakeholders must come together to address these issues nationally and genuinely collaborate to work towards a better future for autistic people in Australia.

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