AutismCRC

Mind the Gap:

Addressing autism research and translation gaps by aligning research with community priorities and experiences (Australia and Aotearoa New Zealand)

Final Report

Dawn Adams, Megan Walsh, Timea Molnar, Halle Wiblen, Kate Simpson, Chris Paradisis, Simon Bury, Larah van der Meer, Chanelle Moriah, Jac den Houting, Abby Sesterka

June 2026



LA TROBE UNIVERSITY

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AUTISM NZ
Every step together

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ISBN: 978-1-922365-71-2

Citation: Adams, D., Walsh, M., Molnar, T., Wiblen, H., Simpson, K., Paradisis, C., Bury, S., van der Meer, L., Moriah, C., den Houting, J., & Sesterka, A. (2026). *Mind the Gap: Addressing autism research and translation gaps by aligning research with community priorities and experiences (Australia and Aotearoa New Zealand)*. Autism CRC.

Copies of this report can be downloaded from the Autism CRC website **autismcrc.com.au.**

Acknowledgements

The authors acknowledge the financial support of Autism CRC. Staff and non-staff in kind were provided by Autism CRC members. The research team would like to acknowledge the time of each community member who made a submission to the consultations, or those who participated in the priority-setting studies. We are grateful for the generous assistance of Dr Lisa Marie Berry and Professor Laurie McLay who provided invaluable guidance that informed our searches for data for Aotearoa New Zealand grants.

Autism CRC

Autism CRC is the independent national source of evidence for best practice in relation to autism across the lifespan and the spectrum.

We provide the national capacity to develop and deliver evidence-based outcomes through our unique collaboration with autistic people, families, professionals, services providers, researchers, and government. Together, we are addressing agreed needs and co-producing outputs with these stakeholders for the benefit of the community.

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

autismcrc.com.au

A note on terminology

We recognise that when referring to individuals on the autism spectrum, there is no one term that suits all people. In our published material and other work, we use the terms 'autistic person', 'person on the autism spectrum' or 'person on the spectrum'. The term 'autistic person' uses identity first language, which reflects the belief that being autistic is a core part of a person's identity.

Autism Spectrum Disorder (ASD) is diagnostic terminology used by the healthcare sector and is used in the context of a person being 'diagnosed with Autism Spectrum Disorder'.

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Executive Summary

Why did we do this project?

Autism research and service investment have expanded significantly across Australia and Aotearoa New Zealand over recent decades. Yet outcomes for autistic people remain widely described as unacceptably poor.

Autistic people, families, and professionals consistently report long waitlists, high costs, fragmented systems, inaccessible environments, and persistent failures of inclusion. Yet at the same time, research activity continues to grow. What has been less clear is whether research activity reflects what autistic people and their communities identify as most important. This project was undertaken to examine that alignment.

Specifically, we asked: To what extent does current autism research in Australia and Aotearoa New Zealand reflect the priorities and concerns identified by autistic people and their communities?

To address this question, four complementary elements were brought together:

1. a mapping of community-raised issues from existing publicly available major Australian and Aotearoa New Zealand consultation responses
2. a systematic review of autism research priorities identified by autistic people, families, professionals, and researchers from Australia and Aotearoa New Zealand
3. a systematic mapping of autism research published between 2023 and 2025 in Australia and Aotearoa New Zealand
4. a portfolio analysis of autism research funding awarded in Australia and Aotearoa New Zealand between 2018 and 2025.

Individually, each element provides important insight. When combined, they allow a clearer view of where research is responding to community issues and research priorities, and more importantly, where gaps in both research knowledge and knowledge translation remain.

Who worked on this project?

This project was led by a multidisciplinary, cross-institution team spanning Australian and Aotearoa New Zealand research centres and autism organisations. The team included autistic researchers, other neurodivergent researchers, and parents of neurodivergent children.

This combination of lived and professional expertise informed the framing of the research questions, the analytical approach, and the interpretation of findings.

What work was done in the project?

The four integrated elements in the project each examined a different part of the research-practice process and are described below. By integrating each of these lenses, what the autistic and autism community say matters, what research stakeholders prioritise, and what research is currently being undertaken was examined.

Community-identified issues

We conducted a desktop mapping review of 1,575 public submissions from preexisting Australian consultation processes and incorporated findings from the Aotearoa New Zealand project, How do we get Autism Support Right in Aotearoa New Zealand? Issues raised in submissions were classified according to eight pre-defined domains that correspond to the areas, highlighted in the report by the Select Committee on Autism, in which autistic people experience significantly poorer outcomes: diagnosis, early intervention and supports, education, employment, housing and independent living, justice system, physical health services, and mental health services. Issues that did not align with these domains were grouped into an 'other' to ensure they were considered in the process.

Research priority-setting studies

Eight Australian and Aotearoa New Zealand priority-setting studies (2019–2025), involving more than 2,500 participants, were systematically reviewed. Identified priorities were inductively coded and also mapped to the same eight domains used in the community issues section.

Published research activity (2023–2025)

Twenty-three academic databases were searched for papers that had the keyword "autis*" in the title or abstract. This resulted in 27,609 title and abstracts to search through. From this, 613 published studies were identified as being Australian or Aotearoa New Zealand autism research (83.2% of which were Australian). This included 318 which had autistic people as participants. Each study was coded into the eight domains (diagnosis, early intervention and supports, education, employment, housing and independent living, justice system, physical health services, and mental health services) or 'other' as noted above. Each article was also explored for how it reported participant demographics.

Research funding portfolio analysis (2018–2025)

Autism research grants funded between 2018 and 2025 were identified for Australia and Aotearoa New Zealand. Grants were coded using the 2017 Interagency Autism Coordinating Committee (IACC) Strategic Plan framework to allow comparison with previous portfolio analyses. Grants were also coded against the community issue framework where there was clear and direct alignment with a community-identified issue. This allowed research investment to be examined both by established research funding categories and by alignment with lived/living experience priorities.

What was found in the project?

Issues reported in community consultations

Issues were identified across each of the eight domains (and 'other') per country. However, across both countries, autistic people, families, and professionals consistently identified issues around

- limited autism understanding and training across key sectors
- long waits, high costs, and fragmented pathways to diagnosis and support
- inaccessible environments, including sensory and communication barriers
- poor coordination across health, education, disability, and social systems, and
- significant gaps in adult supports.

Education was the most frequently raised issue in Australian consultations. In Aotearoa New Zealand, mental health and early support pathways were particularly prominent.

The consultation materials provided limited insight into intersectional groups including autistic people with high support needs, First Nations peoples, culturally and linguistically diverse (CALD) or culturally and racially marginalised (CARM) communities, LGBTQIA+ autistic people, non-speaking autistic people, and others whose experiences are often marginalised.

Research priorities identified by the community

Across priority-setting studies, the most consistently endorsed research priorities when coded inductively (i.e.,categories led by the data), were in the area of:

- community understanding, acceptance, and inclusion (raised in 87.5% of studies)
- mental and physical health (87.5%)
- supports and services (75%)
- education (75%)
- employment (62.5%).

The community prioritised hearing lived experience in 50% of the research priority setting studies.

When coded into the eight domains used to categorise the community issues, the area most often prioritised in the research priority setting exercises was education. This was prioritised in 100% of the studies. Health and mental health were also commonly prioritised. Housing, and Justice were raised less consistently, though they were prioritised in several studies.

Priority-setting samples themselves were not demographically representative, with limited reporting of demographics and therefore poor visibility of participants from intersectional groups.

Focus of Australian and Aotearoa New Zealand autism research published 2023–2025

The focus of autism research activity led by Australian or Aotearoa New Zealand authors and/or reporting on Australian or Aotearoa New Zealand samples was uneven across the eight domains. Most studies focused on early intervention, mental health, and physical health. Very few addressed employment, housing, the justice system, or broader adult life.

Demographic reporting was inconsistent. Age was not reported in one third of studies. Information about support needs, augmentative and alternative communication (AAC) use, cultural background, gender diversity, and geographic location were frequently not reported. As a result, it is often unclear whether research findings are applicable to priority populations.

Portfolio analysis of Australian and Aotearoa New Zealand research funded 2018–2025

Research activity explored through patterns of research investment showed that from 2018–2025, approximately AUD$81.7 million was invested across 138 autism research projects in Australia and NZD$10.9 million across 40 projects in Aotearoa New Zealand.

Funding distribution across IACC (2017) research topics revealed a strong emphasis on basic scientific research in both countries. In Australia, biological research received the largest share of funding (34%), followed by lifespan issues (16%), infrastructure and surveillance (13%), and treatment and intervention research (13%). In Aotearoa New Zealand, biological research also received the largest share of funding (35%), followed by treatment and intervention research (31%) and services research (27%). No grants were identified in Aotearoa New Zealand that aligned with the categories of screening and diagnosis or lifespan issues.

Analysis of project numbers broadly mirrored funding patterns, suggesting that these patterns were not solely attributable to differences in the cost of conducting research in particular areas. Biological research attracted the highest number of grants in both countries. This is notable given that research priority-setting studies in Australia, Aotearoa New Zealand, and internationally consistently identify applied research topics, including health, mental health, services, education, employment, and community inclusion, as higher priorities than basic scientific research.

Overlaps and gaps between community issues, research priorities, research undertaken and research funding in Australia and Aotearoa New Zealand

There are areas of positive alignment, particularly in mental health and aspects of diagnosis. However, in the other domains, there was substantial misalignment between community issues, research priorities, the research undertaken and research funded. This was particularly notable in the domains of housing and independent living and the justice system (where there was very limited research) and cost and affordability of services (which has not been researched specifically), and gender-based inequities, which was prioritised across multiple priority-setting studies but received little research attention or funding. In some domains, evidence exists but does not appear to be translating into improved lived experience.

What happens next?

This review identifies both strengths and structural gaps in the current autism research landscape. This can be of use to researchers in planning their research, to policymakers in funding research, and even to the autistic and autism communities who may wish to support research in specific under researched areas or who may wish to seek out opportunities to learn about the evidence that exists for issues they have prioritised.

Research priority-setting studies across Australia and New Zealand consistently identify (1) health and mental health and (2) community acceptance, understanding, and inclusion as top priorities, each appearing in seven of eight studies (87.5%). While mental health accounts for 13.1% of Australian autism research (2023–25), physical health represents only 7.2%, and there is very limited research focused on community acceptance, understanding, and inclusion—particularly on how to improve these outcomes. This represents a significant gap in an area of clear and sustained community importance.

Education was identified as a priority in six studies (75%) and was the most frequently raised issue in community consultations (20% of submissions). Despite this, only 6.9% of research focused on education. Funding coded directly to education-related community issues was present, particularly for tailored educational delivery and educator awareness, but remained uneven across education priorities. This reflects a clear misalignment between community priorities and current research investment.

The heatmaps in Section 5 highlight gaps where evidence remains limited despite consistent identification in both research and community consultations. Notably, the most commonly identified and highest-ranked gaps are those that cut across multiple domains of life were:

- improving awareness and understanding of autism so as to strengthen inclusive practice across education, healthcare, justice, and employment systems
- reducing delays and barriers to accessing supports across diagnosis, early intervention and physical and mental health systems
- understanding the impact of physical environments to inform more accessible and inclusive settings across sectors, including education and healthcare.

Prioritising these cross-cutting areas presents a strategic opportunity for government to maximise impact of research investment. Autistic people do not experience life within discrete policy or service silos; challenges across areas such as education, health and employment, are interconnected and often compounding. Research that addresses these intersections is more likely

to deliver sustained impact by enabling coordinated policy responses, improving service integration, and targeting shared priorities identified by the community.

The findings of this project also highlight the importance of considering research funding as part of the broader autism research ecosystem. While some highly ranked community priorities were reflected in funded research grants, other prominent concerns, including affordability of services, environmental accessibility, suitable supported accommodation, and gender-based inequities, received little or no identifiable research investment. Addressing these gaps will require not only increased research activity but also funding mechanisms that explicitly encourage alignment between community priorities, policy objectives, and research investment.

To improve outcomes, future effort should also focus on:

- strengthening demographic reporting in research to ensure visibility of priority populations
- increasing emphasis on implementation and translation deliverables within funded research grants, with community and service collaborations occurring from project inception
- aligning research investment with lived experience priorities and policy agendas.

Strengthening alignment between community priorities, research activity and funding, and system reform so as to improve real-world outcomes for autistic people is not simply about increasing research or funding volume. It requires a deliberate focus on research that reflects the complexity of autistic people's lives and is purposefully designed to inform practical, system-wide improvement. Central to this is improving research translation by embedding researcher-community collaborations into every step of the research process. With stronger alignment, accountability, and a focus on translation, research can more effectively drive improvements in policy, service delivery, and practice, supporting inclusive, accessible, and equitable systems across the lifespan.

1. Issues reported by members of the autistic and autism communities in public consultations

1.1 Overview

In order to identify community issues, concerns, and lived or living experience perspectives already described through public submissions, we conducted a structured review of publicly available consultation submissions and discussion materials generated through major state and national autism policy processes. Issues identified within these materials were organised according to eight pre-defined domains.

1.2 Community consultation responses included

Existing, publicly available submissions to public consultations were selected because they represent large-scale, formal mechanisms through which autistic people, families, professionals, and organisations were explicitly invited to articulate priorities, barriers, and reform recommendations. As such, they provide a rich description of community-initiated concerns made within defined policy contexts which could then be read and coded for this section of the report. By coding submissions across multiple jurisdictions where available (e.g., federal and state) and across multiple service domains, we aimed to identify issues raised consistently across consultation processes. For Australia, individual submissions or reports summarising submissions to the other states or territories with autism strategies (i.e., South Australia, Victoria) were checked, but these were not publicly available. Broad summary reports (i.e., those that did not report on the proportion of people reporting specific issues) were not included as these do not go into the detail required for the coding process of this work.

This mapping provides a structured synthesis of issues raised in existing public consultation material. It highlights concerns already placed on the public record across multiple policy processes, however, it is important to recognise that these materials provide a partial account. They may not capture the full range of autistic people's experiences, service interactions, or unmet needs, particularly for people less able to participate in public consultation processes.

All materials included in this section were drawn from publicly available submissions and reports published on official government or organisational websites. Individuals and organisations who made submissions to these inquiries and consultations did so with the understanding that their contributions would be published as part of a public record. The synthesis of issues did not involve any contact with submitters, access to private data, or use of unpublished material. No attempts were made to identify individuals beyond the information already available in the public domain. The review utilised publicly available consultation materials and did not involve contact with contributors, access to private information, or collection of new data. Therefore it does not meet the National Statement definition of human research and therefore did not require ethical review.

The structured review for the Mind the Gap project aligns with the original purpose of the submissions: to articulate community concerns, priorities, and lived or living experiences in order to inform policy and system reform. The coding process therefore represents a structured synthesis of issues already placed into the public record for the purpose of improving services and outcomes for autistic people.

While a similar process was employed to identify community issues in Aotearoa New Zealand, there were some differences in execution. Accordingly, this section will first focus on the Australian context and then, in Section 1.7, move to the Aotearoa New Zealand context. This was done for community issues to respect the local social, cultural, and institutional context of community experiences.

1.3 Australian community issues: Sources included

1.3.1 Senate select committee on autism (Parliament of Australia)

The Select Committee on Autism was established by the Australian Senate in 2019 to inquire into support, services and life outcomes for autistic people across the lifespan. The Committee called for public submissions and held hearings nationally.

- **Consultation period:** Consultation occurred over 2020, with the closing date for submissions being 17 July 2020.
- **Source material coded:** All 168 publicly available written submissions published on the Australian Parliament website, accessed via https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Autism/autism/Submissions

These submissions were made in response to a formal parliamentary inquiry and reflect individual, family, organisational, professional, and advocacy perspectives on systemic barriers, service gaps, and reform priorities.

1.3.2 Parliament of Western Australia inquiry into support for autistic children and young people in schools

In 2022–2023, the Parliament of Western Australia's Education and Health Standing Committee conducted an inquiry into the adequacy of supports for autistic children and young people in schools. The inquiry called for written submissions from the public and conducted hearings.

- **Consultation period:** Submissions opened on 18th May 2023 and closed 13th July 2023. The online discussion boards that remained available after closing on 13th July 2023 were coded..
- **Source material analysed:** All publicly available written submissions published on the Western Australia (WA) Parliament website, accessed via https://www.parliament.wa.gov.au/Parliament/commit.nsf/(InqByName)/Inquiry+into+support+for+autistic+children+and+young+people+in+schools#Submissions

Those making submissions were told the Inquiry would consider three areas: 1. The prevalence of autism in WA and projected demand for support in schools; 2. Current support available for autistic students in WA schools, including consideration of how (a) evidence-based practices are implemented across the school system, and (b) school supports are coordinated with other service areas to respond to the needs of autistic students and their families; and 3. Strategies in other jurisdictions that support school systems to respond to the needs of autistic students, and the applicability of those strategies to WA.

Note: Although this inquiry focused on schools, people did also report issues in other areas. These have been included in summary tables, but any relatively low prevalence compared to other

consultations should be interpreted with consideration to the topic of the inquiry.

1.3.3 National Autism Strategy – Public consultation (Australian Government)

The development of the National Autism Strategy (NAS) included a consultation process run by The Social Deck (commissioned by the Australian Government) and an additional consultation process on the draft NAS. Community members, including autistic people, families, service providers, researchers, and organisations, were invited to contribute through written submissions and online engagement processes, including publicly visible discussion board posts.

- **Consultation period:** Consultation on what should be covered in the NAS occurred in 2023. Over 2,000 people participated, but not all submissions were publicly available. The online discussion boards that remained available after closing on 30th October 2023 were coded. Consultation on the draft NAS occurred between 2nd April and 31st May 2024.
- **Source material analysed:** Publicly available written submissions from https://engage.dss.gov.au/developing-the-national-autism-strategy/developing-the-national-autism-strategy-submissions/ and accessible discussion board posts from https://nas.thesocialdeck.com.au/

Submissions were made in response to the prompt, "We want to see and hear your ideas about what should go into the National Autism Strategy and how it should work. In particular, we're looking for ideas under 4 discussion areas: social inclusion; economic inclusion; diagnosis, services and supports; health and mental health."

1.3.4 Autism CRC – National Autism Strategy and National Roadmap reports

Autism CRC, with its national partner network, undertook sector-wide consultation and evidence synthesis processes to inform both the National Autism Strategy (NAS) and the National Roadmap to Improve the Health and Mental Health of Autistic People.

- **Consultation period:** Submissions opened on 18th May 2023 and closed 13th July 2023.
- **Reports analysed:**
  - Report of the Research Evidence and Policy Landscape Mapping to Inform the National Autism Strategy
  - Report of the Co-design consultation services for the National Roadmap to Improve the Health and Mental Health of Autistic People.

These reports synthesise community consultation from over 1,000 community members who were asked to comment on eight domains: diagnosis, early intervention and supports, education, employment, housing and independent living, justice system, mental health services, and physical health services. These correspond to the domains highlighted in the report by the Select Committee

on Autism.

1.4 Australian community issues: Approach to synthesising issues

1.4.1 Stage 1: Who made submissions to the public consultations?

The contributors to the original public submissions were invited to submit their responses through a series of open consultation processes that occurred in Australia between 2020 and 2023. Invitations were publicly disseminated and individuals self-selected to participate. Participation was voluntary and contributors provided input based on their interest and/or experience relevant to the topic. To provide the context regarding the representativeness of submissions and whether the submissions reflected diverse perspectives within the autistic and autism community, demographic information (where reported) was collated. This included information on their relationship to autistic people, gender, age, self-reported co-occurring conditions and/or intersectional identities, cultural identity, and geographic location (see Table 1.1). The demographic information of contributors was not reported in all submissions or in all consultation processes.

1.4.2 Stage 2: What did the submissions to the public consultations report on?

Each document and submission was systematically reviewed to identify, categorise, and summarise concerns and issues raised by the community member. Issues were first categorised across the pre-determined domains of diagnosis, early intervention and supports, education, employment, housing and independent living, justice system, physical health services, and mental health services. Issues raised that were outside of these areas or that cut across multiple areas (e.g., autistic leadership) were categorised as 'other'.

Within each domain, recurring issues identified across consultation materials were grouped into common issues to facilitate synthesis and reporting. These issues were developed iteratively from the information provided in the consultation materials. In this way, no assumptions were imposed about what responses 'should' report on; instead, the issues identified were grounded in community perspectives.

Every submission was read and systematically grouped alongside other similar responses so as to represent shared concepts or issues. Given the diversity of experiences shared, this process initially produces a large number of codes. Related codes are then organised into broader categories.

To identify the most common responses, the number of responses contributing to each category is calculated. Reporting frequency in this way provides an indication of how widespread an issue is; it does not reflect the severity of impact of any issue. An issue mentioned by fewer people may still have profound effects on those who experience it. The percentage of people raising each issue was calculated in relation to the total number of people making a submission to that report, rather than the number of people commenting on each area. For example, 24.8% (n = 38) of all submitters to the Senate Select Committee commented on a lack of autism awareness, understanding, and/or training among educators, including knowledge of autism's heterogeneity and the diverse needs of autistic students.

1.5 Australian community issues: Findings

1.5.1 Stage 1: Who made submissions to the public consultations?

Submissions were made by 1,575 individuals across the four public sources. Table 1.1 summarises the demographic details of those contributing to the consultations who disclosed demographics (115 of these did not provide any demographic information in their submission). It should be noted that some individuals identified with multiple groups (e.g., an autistic individual and a parent, family member, or caregiver of an autistic individual). As a result, the total percentage is greater than 100%.

Table 1.1: Characteristics (as reported in individual submissions or summary reports) of those who contributed individual submissions or whose data are reported in the reports

Demographic group	Contributor characteristics (where reported in submissions)	% of total submissions reporting this characteristic Total *N* = 1,575	% of submissions that reported each characteristic in their submission, split by source				
			Senate Select Committee (*N* = 153)	NAS Submissions (*N* = 54)	Parliament of WA Inquiry (*N* = 77)	NAS Discussion Boards (*N* = 273)	Autism CRC Reports (*N* = 1,018)
Stakeholder group	Autistic individual	38%	18%	35%	5.2%	46%	42%
	Parent, family member, or caregiver of an autistic individual	43%	18%	17%	49%	14%	56%
	Educational professional	15%	5.9%	7.4%	25%	1.5%	10%
	Allied health professional	14%	14%	7.4%	7.8%	1.5%	17%
	Mental health professional	7.2%	4.6%	7.4%	1.3%	0.0%	10%
	Researcher	7.4%	4.6%	7.4%	3.9%	0.37%	10%
	Advocacy / support agency representative	4.7%	30%	31%	13%	0.37%	0.0%
	Government agency representative	1.1%	7.8%	1.9%	5.2%	0.37%	0.0%
	Not stated	7.3%	1.3%	1.9%	5.2%	40%	0.0%

Demographic group	Contributor characteristics (where reported in submissions)	% of total submissions reporting this characteristic Total *N* = 1,575	% of submissions that reported each characteristic in their submission, split by source				
			Senate Select Committee (*N* = 153)	NAS Submissions (*N* = 54)	Parliament of WA Inquiry (*N* = 77)	NAS Discussion Boards (*N* = 273)	Autism CRC Reports (*N* = 1,018)
Gender identity	Female	54%	14%	28%	7.8%	9.2%	77%
	Male	8.9%	2.0%	1.9%	1.3%	1.1%	13%
	Non-binary	4.6%	0%	1.9%	0.0%	0.0%	7%
Age range (years)	Under 16	0.19%	0.65%	0.0%	1.3%	0.37%	0.0%
	16–30	0.57%	2.0%	7.4%	0.0%	0.73%	0.0%
	31–50	0.64%	3.3%	3.7%	0.0%	1.1%	0.0%
	51–65	0.38%	1.3%	5.6%	0.0%	0.37%	0.0%
	66+	0.19%	1.3%	0.0%	0.0%	0.37%	0.0%

Demographic group	Contributor characteristics (where reported in submissions)	% of total submissions reporting this characteristic Total *N* = 1,575	% of submissions that reported each characteristic in their submission, split by source				
			Senate Select Committee (*N* = 153)	NAS Submissions (*N* = 54)	Parliament of WA Inquiry (*N* = 77)	NAS Discussion Boards (*N* = 273)	Autism CRC Reports (*N* = 1,018)
Self-reported co-occurring conditions and/or intersectional identities	LGBTQIA+	11%	0.65%	3.7%	0.0%	0.37%	17%
	Physical disability	8.1%	0.0%	5.6%	1.3%	0.37%	12%
	Intellectual disability	1.3%	0.0%	0.0%	0.0%	0.0%	2.0%
	Mental health diagnosis	0.38%	0.65%	5.6%	0.0%	0.73%	0.0%
	Augmentative and alternative communication (AAC) user	2.0%	0.0%	0.0%	0.0%	0.0%	3.1%
	Very high or complex support needs	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%
	Non-speaking	0.06%	0.0%	0.0%	0.0%	0.0%	0.10%
	Living in home care or supported accommodation	0.25%	0.0%	0.0%	0.0%	0.0%	0.39%
	Other neurodivergent diagnosis	0.76%	0.0%	3.7%	1.3%	3.3%	0.0%

Demographic group	Contributor characteristics (where reported in submissions)	% of total submissions reporting this characteristic Total *N* = 1,575	% of submissions that reported each characteristic in their submission, split by source				
			Senate Select Committee (*N* = 153)	NAS Submissions (*N* = 54)	Parliament of WA Inquiry (*N* = 77)	NAS Discussion Boards (*N* = 273)	Autism CRC Reports (*N* = 1,018)
Cultural identity	Aboriginal and/or Torres Strait Islander	1.3%	0.0%	0.0%	0.0%	0.0%	2.0%
	CALD/CARM	5.7%	2.0%	3.7%	0.0%	1.1%	8.0%
Geographic location	City / metro	0.06%	0.65%	0.0%	0.0%	0.0%	0.0%
	Rural / regional	0.06%	0.0%	1.85%	0.0%	0.0%	0.0%

Note. Not all submissions reported contributor demographics. Therefore, the figures reflect the proportion of submissions that included demographic information, not the proportion of all submissions made by each demographic group.

Overall, parents, family members, or caregivers of autistic people made the highest number of submissions to the consultations, making up 43% of the submissions. Autistic individuals made 38% of the submissions. Within the submissions made, 54% identified as female, 11% of the individuals stated they are LGBTQIA+ and 8.1% stated they have a physical disability. In terms of cultural identity, there was limited diversity with only 1.3% identifying as Aboriginal and/or Torres Strait Islander and 5.7% identifying as culturally or linguistically diverse (CALD) or culturally and racially marginalised (CARM).

Limited submissions described age and only two individuals elected to provide information about their geographic location. As a result, it is not possible to draw accurate conclusions about the age range and geographic information of all contributors.

There was a limited number of contributors who identified as having co-occurring conditions which included intellectual disabilities (1.3%), mental health diagnoses (0.38%), and other neurodivergent diagnoses (0.76%). Only 2% of contributors were AAC users. Additionally, merely one contributor was non-speaking and there were no contributors who identified as having very high or complex support needs.

1.5.2 Stage 2: Issues identified in the public submissions

Across the sources, 1,575 publicly available submissions were identified and coded to summarise issues raised by autistic people as reported by both autistic individuals and other stakeholders. Because a single submission could raise more than one issue , a total of 10,842 issue mentions were coded. In coding community-reported issues, all submissions were considered together to capture the full range of issues experienced or observed across the community. While contributions came from different perspectives (autistic individuals, parents, teachers, and others), this approach provides a broad summary of the issues raised across public consultation material. The Autism CRC Report of the Research Evidence and Policy Landscape Mapping to Inform the National Autism Strategy, that had a large and broad sample, reports a detailed description of the prevalence of issues separately by informant group.

The 10,842 issue mentions were coded into one of eight pre-determined domains. Issues that could not be coded into one of these eight domains were coded into 'other'. The domains (and other), in order of frequency of reporting, are:

1. education (n = 2,253, 20.8% of issues)
2. physical health services (n = 1,537, 14.2%)
3. employment (n = 1,471, 13.6%)
4. mental health services (n = 1,422, 13.12%)
5. diagnosis (n = 1,132 issues, 11.5%)
6. early intervention and supports (n = 666, 6.1%)
7. housing and independent living (n = 473, 4.4%)
8. justice system (n = 350, 3.2%).

There were also 1,421 (13.11% of all issues) coded into 'other'. In the following sections, these domains are further broken down into specific issues, which are ranked by how frequently they were reported within each domain.

1.5.2.1 Diagnosis

In total, 1,132 issues related to diagnosis were reported, making up 11.5% of total issues coded. It was the 6th most frequently reported domain. The issues raised within this domain were coded into the following:

- a lack of autism awareness, understanding, and/or training for diagnosis, including knowledge of autism's heterogeneity and associated needs
- a lack of knowledge and specialised care for those with co-occurring conditions
- a lack of a multidisciplinary and comprehensive approach to assessment and diagnosis
- delays in assessment or diagnosis
- gender-based inequities in access to or delivery of assessment and diagnosis
- high costs associated with accessing assessment and diagnosis
- issues with the reliability of diagnostic and assessment methods and processes.

Table 1.2 ranks the seven issues raised regarding autistic people's experience with diagnosis. The issues are listed from most frequently raised to least frequently raised overall.

Table 1.2: Most frequently reported issues in relation to autistic people's experience with diagnosis

Rank	Issue raised in submission that relates to autistic people's experiences with diagnosis	Quote(s) to reflect lived/ living experience	% of submissions coded to this issue (overall) Total *N* = 1,575	% of submissions coded to issue				
				Senate Select Committee Total (*N* = 153)	NAS Submissions Total (*N* = 54)	Parliament of WA Inquiry Total (*N* = 77)	NAS Discussion Boards Total (*N* = 273)	Autism CRC Reports Total (*N* = 1,018)
1	**Delays in assessment or diagnosis** (e.g., prolonged referral process, limited access to specialists)	*"Long wait times for starting the diagnosis journey."* (ID 3383; autistic community and other stakeholder group; Autism CRC Report) *"The wait to access child development services in the public system such as Paediatricians and Speech Pathologists, to just start the drawn out process of getting a formal diagnosis is unreasonable."* (ID 2344; parent of primary-school-aged children; Parliament of WA Inquiry)	24.4%	16.3%	38.9%	3.9%	7.0%	31.0%

Rank	Issue raised in submission that relates to autistic people's experiences with diagnosis	Quote(s) to reflect lived/ living experience	% of submissions coded to this issue (overall) Total *N* = 1,575	% of submissions coded to issue				
				Senate Select Committee Total (*N* = 153)	NAS Submissions Total (*N* = 54)	Parliament of WA Inquiry Total (*N* = 77)	NAS Discussion Boards Total (*N* = 273)	Autism CRC Reports Total (*N* = 1,018)
2	**High costs associated with accessing assessment and diagnosis** (e.g., expensive psychological evaluations, diagnostic fees)	*"I was shocked how expensive an autism diagnosis was at year 2020."* (ID 3223; autistic CALD woman; NAS Discussion Boards) *"There was considerable expense involved in being assessed by a clinical psychologist."* (ID 1626; 25-year-old autistic adult; NAS Submission)	20.9%	14.4%	35.2%	1.3%	9.2%	25.7%
3	**A lack of autism awareness, understanding, and/or training for diagnosis, including knowledge of autism's heterogeneity and associated needs** (e.g., diagnostic professionals do not recognise how autistic traits present differently across individuals or know how to adapt their assessment practices accordingly; families can sometimes find it difficult to identify signs of autism)	*"Ensure services assessing children for autism have staff with the expertise required to rule out other diagnostic possibilities (genetic, psychiatric, other neurodevelopmental)."* (ID 1134; university; Senate Select Committee) *"Families not informed about what autism is and what the diagnosis process involves."* (ID 3393; autistic community and other stakeholder group; Autism CRC Report)	19.2%	15.7%	31.5%	0.0%	7.7%	23.6%

Rank	Issue raised in submission that relates to autistic people's experiences with diagnosis	Quote(s) to reflect lived/ living experience	% of submissions coded to this issue (overall) Total *N* = 1,575	% of submissions coded to issue				
				Senate Select Committee Total (*N* = 153)	NAS Submissions Total (*N* = 54)	Parliament of WA Inquiry Total (*N* = 77)	NAS Discussion Boards Total (*N* = 273)	Autism CRC Reports Total (*N* = 1,018)
4	**A lack of multidisciplinary and comprehensive approach to assessment and diagnosis** (e.g., limited input from professionals across fields and lack of thoroughness, leading to incomplete or inaccurate diagnoses)	*"It's crucial to consider the diverse nature of Autism and advocate for a customised diagnostic and assessment approach."* (ID 2692; parent of an autistic son; Parliament of WA Inquiry) *"Best practice [diagnosis] should be a multi-disciplinary approach with a paediatrician, psychologist and occupational or speech therapist."* (ID 244; autism support organisation; Senate Select Committee)	6.2%	11.8%	20.4%	2.6%	2.6%	5.9%
5	**Issues with the reliability of diagnostic and assessment methods and processes** (e.g., inconsistent criteria used by professionals, use of inaccurate tools)	*"There are significant differences between methods of diagnosis, with some taking one visit to a paediatrician and others requiring multiple assessments and consultations."* (ID 438; inclusive early learning provider; Senate Select Committee) *"The need for accurate assessment and diagnosis is important to enable an individual's needs to be understood to inform appropriate interventions and referral pathways."* (ID 2498; government department; Parliament of WA Inquiry)	4.1%	15.0%	7.4%	1.3%	1.5%	3.2%

Rank	Issue raised in submission that relates to autistic people's experiences with diagnosis	Quote(s) to reflect lived/ living experience	% of submissions coded to this issue (overall) Total *N* = 1,575	% of submissions coded to issue				
				Senate Select Committee Total (*N* = 153)	NAS Submissions Total (*N* = 54)	Parliament of WA Inquiry Total (*N* = 77)	NAS Discussion Boards Total (*N* = 273)	Autism CRC Reports Total (*N* = 1,018)
6	**Gender-based inequities in access to or delivery of assessment and diagnosis** (e.g., differences in service access or support based on gender, leading to underdiagnosis or misdiagnosis in some groups)	*"Autism in girls is still underdiagnosed and particularly in primary school they tend to mask quite successfully. This was the case for my daughter. As she has high intelligence, her average grades meant she did not appear at educational risk and socially she was able to mimic her peers until at least around age 9 or 10. Signs of autism were dismissed largely as parental fault or immaturity by teachers."* (ID 2585; mother of autistic children; Parliament of WA Inquiry) *"In order to find a specialist to diagnose ASD and ADHD as a female is next to impossible."* (ID 3127; autistic and ADHD woman; NAS Discussion Board)	3.3%	13.1%	27.8%	3.9%	5.1%	0.0%

Rank	Issue raised in submission that relates to autistic people's experiences with diagnosis	Quote(s) to reflect lived/ living experience	% of submissions coded to this issue (overall) Total *N* = 1,575	% of submissions coded to issue				
				Senate Select Committee Total (*N* = 153)	NAS Submissions Total (*N* = 54)	Parliament of WA Inquiry Total (*N* = 77)	NAS Discussion Boards Total (*N* = 273)	Autism CRC Reports Total (*N* = 1,018)
7	**A lack of knowledge and specialised care for those with co-occurring conditions** (e.g., limited understanding of how co-occurring conditions like ADHD, anxiety, or intellectual disability affect assessment, diagnosis, and treatment)	*"It is very common for an Autistic person to have other co-existing "conditions" such as anxiety, ADHD, dyslexia, dysgraphia etc. This makes our children complex people who need highly skilled and attuned professionals around them to provide them and their families and carers the most appropriate care and advice. Such professionals are difficult to find and to access."* (ID 2135; disability organisation; NAS Submission) *"Educate mental and physical healthcare and service providers about the unique clinical presentation of co-occurring conditions in autism and train them on the appropriate use of validated tools to identify and treat these conditions."* (ID 630; university autism research centre; Senate Select Committee)	1.2%	5.2%	14.8%	0.0%	1.1%	0.0%

1.5.2.2 Early intervention and supports

In total 666 issues related to early interventions and supports were reported, making up 6.1% of total issues raised. It was the 7th most frequently reported domain. The issues raised within this domain were coded into the following three issues:

- delays in accessing early intervention services
- inadequacy of early intervention services
- limited access to early intervention services.

Table 1.3 ranks the three issues raised regarding autistic people's experience with early interventions and supports. The issues are listed from most frequently raised to least frequently raised overall.

Table 1.3: Most frequently reported issues in relation to autistic people's experience with early intervention and supports

Rank	Issue raised in submission that relates to autistic people's experiences with early intervention or supports	Quote(s) to reflect lived/ living experience	% of submissions coded to this issue (overall) Total *N* = 1,575	% of submissions coded to issue				
				Senate Select Committee Total (*N* = 153)	NAS Submissions Total (*N* = 54)	Parliament of WA Inquiry Total (*N* = 77)	NAS Discussion Boards Total (*N* = 273)	Autism CRC Reports Total (*N* = 1,018)
1	**Inadequacy of early intervention services** (e.g., lack of tailoring to individual needs, untrained staff, high costs, use of inappropriate interventions)	*"[Early intervention] therapy is stressful or traumatic (for child/family)."* (ID 3411; autistic community and other stakeholder group; Autism CRC Report) *"...the problematic lack of capacity, appropriate training for those in the ECEI [Early Childhood Early Intervention] stream and the lack of an endorsed national guidelines or quality framework remains."* (ID 1208; neurodevelopment support and advocacy organisation; Senate Select Committee)	17.4%	13.8%	9.3%	13.0%	3.3%	22.5%

Rank	Issue raised in submission that relates to autistic people's experiences with early intervention or supports	Quote(s) to reflect lived/ living experience	% of submissions coded to this issue (overall) Total *N* = 1,575	% of submissions coded to issue				
				Senate Select Committee Total (*N* = 153)	NAS Submissions Total (*N* = 54)	Parliament of WA Inquiry Total (*N* = 77)	NAS Discussion Boards Total (*N* = 273)	Autism CRC Reports Total (*N* = 1,018)
2	**Delays in accessing early intervention services** (e.g., lengthy diagnosis and wait times, delayed identification, restrictive eligibility criteria)	*"Even after receiving a diagnosis, families must endure months of additional assessments, reports, and duplication, which is burdensome and delays critical early intervention."* (ID 1912; autistic woman; NAS Submission) *"I would recommend that all children, regardless of diagnosis, receive services if they are not meeting milestones. We need to address the developmental delay, not wait for a diagnosis."* (ID 1337; mother of a 7-year-old autistic son; Senate Select Committee)	12.7%	11.8%	13.0%	1.3%	0.7%	16.9%
3	**Limited access to early intervention services** (e.g., limited availability of autism-informed early intervention programs, long waitlists, gender-related inequities, emphasis on diagnosis instead of early intervention)	*"Limited availability of early intervention services and trained staff."* (ID 3395; autistic community and other stakeholder group; Autism CRC Report) *"The [state government public guardian] advocates for a strategic and equitable intervention plan that targets concerns such as language development and sensory issues and encompasses all children across the autism spectrum from low to high functioning, rather than an emphasis on diagnosis that targets moderate to severe levels of disability. This early intervention would minimise future reliance on interventions such as adult guardianship in adulthood."* (ID 221; state government public guardian; Senate Select Committee)	12.2%	10.5%	11.1%	0.0%	0.7%	16.5%

1.5.2.3 Education

For education, 2,253 issues were reported, making up 20.8% of total issues raised. It was the most frequently reported domain. This remains true even if all the Parliament of WA Inquiry (that focussed on education) contributors are removed. The issues raised within this domain were coded to the following eight issues:

- a lack of autism awareness, understanding, and/or training among educators, including knowledge of autism's heterogeneity and the diverse needs of autistic students
- educational exclusion or lack of inclusion
- gender-based inequities in access to or delivery of education
- lack of public or community education on autism
- limited access to educational support
- limited collaboration between educators and families to inform decision-making
- limited consideration of environmental support requirements
- limited or inconsistent delivery of education tailored to individual needs and preferences.

Table 1.4 ranks the eight issues raised regarding autistic people's experience with education. The issues are listed from most frequently raised to least frequently raised overall.

Table 1.4: Most frequently reported issues in relation to autistic people's experience with education

Rank	Issue raised in submission that relates to autistic people's experiences with education	Quote(s) to reflect lived/ living experience	% of submissions coded to this issue (overall) Total *N* = 1,575	% of submissions coded to issue				
				Senate Select Committee Total (*N* = 153)	NAS Submissions Total (*N* = 54)	Parliament of WA Inquiry Total (*N* = 77)	NAS Discussion Boards Total (*N* = 273)	Autism CRC Reports Total (*N* = 1,018)
1	**A lack of autism awareness, understanding, and/or training among educators, including knowledge of autism's heterogeneity and the diverse needs of autistic students** (e.g., educators do not recognise how autistic traits present differently across students or know how to adapt classroom strategies, learning support, and assessments accordingly)	*"Lack of training and education about autism."* (ID 3424; autistic community and other stakeholder group; Autism CRC Report) *"This is what the school system needs: professional development on autism, ADHD, anxiety."* (ID 2686; mother of an autistic girl; Parliament of WA Inquiry)	36.7%	24.8%	46.3%	55.8%	7.7%	44.3%
2	**Limited consideration of environmental support requirements** (e.g., lack of physical accessibility, absence of sensory-friendly classrooms, or inadequate accommodations for students)	*"The school or learning environment is not designed for autistic students and/or is not sensory friendly."* (ID 3414; autistic community and other stakeholder group; Autism CRC Report) *"Include strategies for reducing physical barriers that create sensory overload for Autistic students such as cluttered classrooms, bright lighting and strict uniform policies."* (ID 2122; disability organisation; NAS Submission)	36.3%	4.6%	20.4%	33.8%	3.3%	51.0%

Rank	Issue raised in submission that relates to autistic people's experiences with education	Quote(s) to reflect lived/ living experience	% of submissions coded to this issue (overall) Total *N* = 1,575	% of submissions coded to issue				
				Senate Select Committee Total (*N* = 153)	NAS Submissions Total (*N* = 54)	Parliament of WA Inquiry Total (*N* = 77)	NAS Discussion Boards Total (*N* = 273)	Autism CRC Reports Total (*N* = 1,018)
3	**Limited or inconsistent delivery of education tailored to individual needs and preferences** (e.g., educational content and teaching methods not adapted to a student's sensory, communication, or cognitive needs, or absence of individualised plans)	*"I am extremely discouraged as a parent, as I feel my son is not going to get the opportunity to be educated in the way he is capable of learning. I suspect this is partly due to inexperienced and unqualified educators when supporting neurodivergent students, but mostly, it will be about a significant lack of resources that could allow educators to tailor the educational experience the autistic person needs."* (ID 1402; autistic parent of a 5-year-old autistic son; Senate Select Committee) *"Instructional approaches do not consider the needs of autistic children."* (ID 3416; autistic community and other stakeholder group; Autism CRC Report)	31.2%	27.5%	31.5%	39.0%	8.1%	37.4%
4	**Educational exclusion or lack of inclusion** (e.g., lack of social inclusion, misconceptions about autistic students' abilities, classroom removal/suspension)	*"Autistic children are excluded and/or isolated; difficulty making friends."* (ID 3426; autistic community and other stakeholder group; Autism CRC Report) *"Critically review use of suspension and expulsion for neurodivergent children in schools."* (ID 2289; parents of two autistic boys; Parliament of WA Inquiry)	20.3%	5.9%	16.7%	28.6%	4.0%	26.4%

Rank	Issue raised in submission that relates to autistic people's experiences with education	Quote(s) to reflect lived/ living experience	% of submissions coded to this issue (overall) Total *N* = 1,575	% of submissions coded to issue				
				Senate Select Committee Total (*N* = 153)	NAS Submissions Total (*N* = 54)	Parliament of WA Inquiry Total (*N* = 77)	NAS Discussion Boards Total (*N* = 273)	Autism CRC Reports Total (*N* = 1,018)
5	**Limited access to educational support** (e.g., restricted availability, insufficient funding, eligibility requirements)	*"Teachers are already time-poor and overburdened. The unique challenges of teaching children with autism highlights the need for autism services to be available within schools, including appropriate teacher training and effective collaboration with allied health professionals such as speech pathologists and occupational therapists."* (ID 2495; not-for-profit association working to open an Autism School; Parliament of WA Inquiry) *"The current levels of access and attainment for students with disability in the school system is inadequate, discriminatory and lacks a research base. Firstly, attempting to access appropriate supports for students with disability is a stressful process which at its core does not provide the opportunity for students to access supports in order to be on a level playing field like typically developing peers."* (ID 1413; parent of autistic children, autism researcher, and therapist for autistic children; Senate Select Committee)	12.0%	20.9%	18.5%	63.6%	4.0%	8.6%

Rank	Issue raised in submission that relates to autistic people's experiences with education	Quote(s) to reflect lived/ living experience	% of submissions coded to this issue (overall) Total *N* = 1,575	% of submissions coded to issue				
				Senate Select Committee Total (*N* = 153)	NAS Submissions Total (*N* = 54)	Parliament of WA Inquiry Total (*N* = 77)	NAS Discussion Boards Total (*N* = 273)	Autism CRC Reports Total (*N* = 1,018)
6	**Lack of public or community education on autism** (e.g., limited public awareness and understanding of autism, absence of educational campaigns)	*"Education programs should be designed to help reduce the stigma that Autistic people face in the community, utilising a neurodiversity framework to disrupt common assumptions about Autism as a pathology."* (ID 1970; mental health organisation; NAS Submission) *"Neurodiversity needs to be openly discussed within society in order to reduce the outdated perception of what autism and ADHD 'look like'."* (ID 2865; demographics not stated; NAS Discussion Board)	4.0%	13.1%	37.0%	0.0%	8.4%	0.0%
7	**Limited collaboration between educators and families to inform decision-making** (e.g., insufficient or unclear information about educational options)	*"Listen to families and what they say they need [in the school system]."* (ID 2683; mother of an autistic girl; Parliament of WA Inquiry) *"I have recently experienced poor communication from a primary school in [state] when I engaged them about enrolling my autistic son into the Specialist Learning Program for children with autism."* (ID 1580; autistic parent of an autistic child; Senate Select Committee)	2.2%	6.5%	11.1%	18.2%	1.8%	0%

Rank	Issue raised in submission that relates to autistic people's experiences with education	Quote(s) to reflect lived/ living experience	% of submissions coded to this issue (overall) Total *N* = 1,575	% of submissions coded to issue				
				Senate Select Committee Total (*N* = 153)	NAS Submissions Total (*N* = 54)	Parliament of WA Inquiry Total (*N* = 77)	NAS Discussion Boards Total (*N* = 273)	Autism CRC Reports Total (*N* = 1,018)
8	**Gender-based inequities in access to or delivery of education** (e.g., differences in service availability or support provided to students across all gender identities)	*"Staff in girls' high schools are prioritised for professional development about the female presentation of ASD."* (ID 908; mother of a 13-year-old autistic daughter; Senate Select Committee) *"Females and ASD prevalence is also increasing and presents another set of challenges for schools as presentation is very different to males."* (ID 2375; educator; Parliament of WA Inquiry)	0.3%	2.0%	0.0%	1.3%	0.0%	0.0%

1.5.2.4 Employment

1,471 issues related to employment were reported, making up 13.6% of total issues raised. It was the 3rd most frequently reported domain. The issues raised within this domain were coded into the following four issues:

- a lack of autism awareness and/or training among employers and employees
- a lack of autistic-specific employment initiatives
- barriers to obtaining and sustaining employment
- workplace exclusion.

Table 1.5 ranks the four issues raised regarding autistic people's experience with employment. The issues are listed from most frequently raised to least frequently raised overall.

Table 1.5: Most frequently reported issues in relation to autistic people's experience with employment

Rank	Issue raised in submission that relates to autistic people's experiences with employment	Quote(s) to reflect lived/ living experience	% of submissions coded to this issue (overall) Total *N* = 1,575	% of submissions coded to issue				
				Senate Select Committee Total (*N* = 153)	NAS Submissions Total (*N* = 54)	Parliament of WA Inquiry Total (*N* = 77)	NAS Discussion Boards Total (*N* = 273)	Autism CRC Reports Total (*N* = 1,018)
1	**Workplace exclusion** (e.g., lack of social inclusion, misconceptions about autistic workers' ability, unsupportive workplace culture)	*"Fitting in – masking."* (ID 3446; autistic community and other stakeholder group; Autism CRC Report) *"While autistic people are in paid employment, we experience a raft of difficulties throughout, including social exclusion within the workplace, difficulty with workplace communication, and bullying and harassment due to our innate differences."* (ID 1701; queer autistic woman; NAS Submission)	40.1%	11.1%	13.0%	0.0%	1.1%	59.4%
2	**Barriers to obtaining and sustaining employment** (e.g., limited workplace adjustments, discrimination, insufficient job support services)	*"However regardless of the workplace setting, I felt that I was working harder to navigate processes, practices and communication that were based on neurotypical ways of being."* (ID 1720; late diagnosed autistic, ADHD and LGBTQIA+ mother; NAS Submission) *"I work in Government, and I know that there is a trend towards Hot Desking e.g., what they are doing at [business district] in order to fit more people into shared spaces.... What I don't think anyone has considered is just how disruptive that is against the Autistic mind."* (ID 2919; autistic adult; NAS Discussion Board)	29.0%	15.7%	22.2%	0.0%	9.2%	38.8%

Rank	Issue raised in submission that relates to autistic people's experiences with employment	Quote(s) to reflect lived/ living experience	% of submissions coded to this issue (overall) Total *N* = 1,575	% of submissions coded to issue				
				Senate Select Committee Total (*N* = 153)	NAS Submissions Total (*N* = 54)	Parliament of WA Inquiry Total (*N* = 77)	NAS Discussion Boards Total (*N* = 273)	Autism CRC Reports Total (*N* = 1,018)
3	**A lack of autism awareness and/ or training among employers and employees** (e.g., limited understanding of neurodiversity, inadequate staff training on inclusive practices)	*"Scaling up of workplace education about Autistic lived experienced provided by Autistic-led organisations."* (ID 2206; organisation for LGBTQIA+ families; NAS Submission) *"It should also focus on upskilling employers and others in the workplace around Autism, how to be ND affirming, and how to communicate with an Autistic person about what adjustments we need. Funding should also be offered for then implementing these adjustments."* (ID 3020; autistic adult; NAS Discussion Board)	16.8%	7.8%	22.2%	0.0%	5.5%	22.2%
4	**A lack of autistic-specific employment initiatives** (e.g., tailored job readiness programs, supported employment pathways, partnerships with inclusive employers)	*"All levels of government need to get serious about overcoming unemployment and under-employment amongst people on the Autism Spectrum, by promoting employment programs and quotas."* (ID 19; political party subgroup; Senate Select Committee) *"I think when workplaces say they are committed to inclusion and diversity, they should actively include neurodivergence as part of this."* (ID 3050; autistic adult; NAS Discussion Board)	7.5%	28.9%	18.5%	0.0%	6.2%	4.6%

1.5.2.5 Housing and independent living

For housing, 473 issues related to housing and independent living were reported, making up 4.4% of total issues raised. It was the 8th most frequently reported domain. The issues raised within this domain were coded into the following three issues:

- a lack of accessible public facilities to support independent living
- a lack of suitable supported accommodation
- limited access to resources and support for developing independent living skills.

Table 1.6 ranks the three issues raised regarding autistic people's experience with housing and independent living. The issues are listed from most frequently raised to least frequently raised overall.

Table 1.6: Most frequently reported issues in relation to autistic people's experience with housing and independent living

Rank	Issue raised in submission that relates to autistic people's experiences with housing and independent living	Quote(s) to reflect lived/ living experience	% of submissions coded to this issue (overall) Total *N* = 1,575	% of submissions coded to issue				
				Senate Select Committee Total (*N* = 153)	NAS Submissions Total (*N* = 54)	Parliament of WA Inquiry Total (*N* = 77)	NAS Discussion Boards Total (*N* = 273)	Autism CRC Reports Total (*N* = 1,018)
1	**A lack of suitable supported accommodation** (e.g., limited availability, inadequate staffing, safety and accessibility concerns)	*"Timely access to public housing as currently there is a long wait list."* (ID 3448; autistic community and other stakeholder group; Autism CRC Report) *"Safety is a big issue – whether it be main roads, waterways, open spaces are all dangerous to young autistics in particular who have no ability to assess risk. Multi story homes, balconies and windows all become jump/fall risks. When looking at accommodation options, it is very difficult to find options that are safe primarily for my son, before I can even entertain affordability, or choice of comfort and preferences."* (ID 1404; autistic parent of a 5-year-old autistic son; Senate Select Committee)	22.3%	11.1%	11.1%	0.0%	1.8%	32.8%
2	**Limited access to resources and support for developing independent living skills** (e.g., managing finances, maintaining a household)	*"Lack of support with the rental process and with understanding a tenant's rights, having pets, routine inspections."* (ID 3456; autistic community and other stakeholder group; Autism CRC Report) *"The challenges experienced by young autistic people in living independently suggests the need for living skills programs such as travel training, meal preparation, money management and budgeting programs."* (ID 1509; peak autism service and support provider; Senate Select Committee)	4.8%	0.7%	0.0%	0.0%	0.0%	7.4%

Rank	Issue raised in submission that relates to autistic people's experiences with housing and independent living	Quote(s) to reflect lived/ living experience	% of submissions coded to this issue (overall) Total *N* = 1,575	% of submissions coded to issue				
				Senate Select Committee Total (*N* = 153)	NAS Submissions Total (*N* = 54)	Parliament of WA Inquiry Total (*N* = 77)	NAS Discussion Boards Total (*N* = 273)	Autism CRC Reports Total (*N* = 1,018)
3	**A lack of accessible public facilities to support independent living** (e.g., inadequate sensory-friendly spaces, physical accessibility barriers)	*"There are only a handful of supermarkets and cinemas that have a 'quiet' session for those who have autism. More cinemas, museums, galleries and supermarkets for instance can have 'lower volume' or 'quiet' session times for those who have auditory sensitivities."* (ID 2883; demographics not stated; NAS Discussion Board) *"If public places such as shopping centres, museums, government offices etc. had regular 'quiet appointment times' at which the environment was adjusted and crowd control was managed with minimal or at least controlled wait times, then accessibility would be vastly improved for autistic people."* (ID 1734; parent of an autistic daughter; NAS Submission)	2.2%	7.2%	18.5%	0.0%	5.1%	0.0%

1.5.2.6 Justice system

Here, 350 issues related to the justice system were reported, making up 3.2% of total issues raised. It was the least frequently reported domain. The issues raised within this domain were coded into the following four issues:

- a lack of autism awareness, understanding, and/or training among criminal justice professionals (e.g., law enforcement, prison staff), including knowledge of autism's heterogeneity and associated needs
- a lack of support, rehabilitation, and reintegration options
- heightened vulnerability in the criminal justice system due to systemic gaps
- overrepresentation of autistic people in the criminal justice system.

Table 1.7 ranks the four issues raised regarding autistic people's experience with the justice system. The issues are listed from most frequently raised to least frequently raised overall.

Table 1.7: Most frequently reported issues in relation to autistic people's experience with the justice system

Rank	Issue raised in submission that relates to autistic people's experiences with the justice system	Quote(s) to reflect lived/ living experience	% of submissions coded to this issue (overall) Total *N* = 1,575	% of submissions coded to issue				
				Senate Select Committee Total (*N* = 153)	NAS Submissions Total (*N* = 54)	Parliament of WA Inquiry Total (*N* = 77)	NAS Discussion Boards Total (*N* = 273)	Autism CRC Reports Total (*N* = 1,018)
1	**A lack of autism awareness, understanding, and/or training among criminal justice professionals (including law enforcement, prison staff), including knowledge of autism's heterogeneity and associated needs** (e.g., law enforcement or prison staff do not recognise how autistic traits present differently across individuals or know how to adapt their practices accordingly)	*"After instructions made in official language, [autistic person] became confused, flapping his hands. The police placed him in protective custody, which was technically the correct thing to do, but [autistic person] did not know what protective custody was. He became frantic with fear, not knowing if he would go to prison or how long he would be detained. It would have been helpful if the young constable had recognised flapping as a sign of autism and understood that he should speak in short, simple sentences that [autistic person] would understand."* (ID 1651; autistic woman; Senate Select Committee) *"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)."* (ID 3465; autistic community and other stakeholder group; Autism CRC Report)	12.6%	9.8%	7.4%	0.0%	1.5%	17.2%

Rank	Issue raised in submission that relates to autistic people's experiences with the justice system	Quote(s) to reflect lived/ living experience	% of submissions coded to this issue (overall) Total *N* = 1,575	% of submissions coded to issue				
				Senate Select Committee Total (*N* = 153)	NAS Submissions Total (*N* = 54)	Parliament of WA Inquiry Total (*N* = 77)	NAS Discussion Boards Total (*N* = 273)	Autism CRC Reports Total (*N* = 1,018)
2	**Heightened vulnerability in the criminal justice system due to systemic gaps** (e.g., lack of accurate autism identification, absence of appropriate safeguards)	*"Increased risk of entering criminal justice system including through manipulation, coercion, or not fully understanding the implications of an act."* (ID 3470; autistic community and other stakeholder group; Autism CRC Report) *"If a woman does not have a diagnosis, it can be extremely difficult for her to receive understanding and justice. Autistic women may be victims of crime or may technically become perpetrators of crime without really wanting to while under the influence of a predator. An unusual demeanour, particularly lack of eye contact, may result in a prejudgment of dishonesty by those involved in the justice system. Fear may lead to mutism or difficulty following instructions. Some plead guilty out of fear and fail to explain their circumstances."* (ID 1462; coalition of autistic women; Senate Select Committee)	4.8%	3.3%	11.1%	0.0%	1.8%	5.8%

Rank	Issue raised in submission that relates to autistic people's experiences with the justice system	Quote(s) to reflect lived/ living experience	% of submissions coded to this issue (overall) Total *N* = 1,575	% of submissions coded to issue				
				Senate Select Committee Total (*N* = 153)	NAS Submissions Total (*N* = 54)	Parliament of WA Inquiry Total (*N* = 77)	NAS Discussion Boards Total (*N* = 273)	Autism CRC Reports Total (*N* = 1,018)
3	**A lack of support, rehabilitation, and reintegration options** (e.g., limited access to autism-informed mental health services, tailored education or employment programs, or community-based support upon release)	*"Explore what supports people with Autism do, or are likely to need to access urgently, upon discharge and consider developing some additional support items for provision of urgent/complex supports in the community at times of transition out of acute healthcare or justice services."* (ID 1043; speech pathologist; Senate Select Committee) *"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)."* (ID 3466; autistic community and other stakeholder group; Autism CRC Report)	4.2%	4.6%	1.9%	0.0%	0.4%	5.6%

Rank	Issue raised in submission that relates to autistic people's experiences with the justice system	Quote(s) to reflect lived/ living experience	% of submissions coded to this issue (overall) Total *N* = 1,575	% of submissions coded to issue				
				Senate Select Committee Total (*N* = 153)	NAS Submissions Total (*N* = 54)	Parliament of WA Inquiry Total (*N* = 77)	NAS Discussion Boards Total (*N* = 273)	Autism CRC Reports Total (*N* = 1,018)
4	**Over-representation of autistic people in the criminal justice system** **(i.e., indicative of systemic issues)**	*"There is an increased rate of interaction with the justice system for autistic people, especially when there is a comorbid psychiatric diagnosis, which compounds social isolation experienced by autistic people. Interaction with the justice system occurs in victim, offender and witness roles."* (ID 1822; psychiatrist organisation; NAS Submission) *"At its most significant level these exclusions from school and community settings can result in autistic students whose behaviours of concern bring them into contact with the justice system."* (ID 1546; behavioural intervention organisation; Senate Select Committee)	0.7%	2.0%	9.3%	0.0%	1.1%	0.0%

1.5.2.7 Physical health services

In total, 1,537 issues related to physical health services were reported, making up 14.2% of total issues raised. It was the 2nd most frequently reported domain. The issues raised within this domain were coded into the following seven issues:

- a lack of autism awareness, understanding, and/or training among physical health professionals, including knowledge of autism's heterogeneity and associated needs
- gender-based inequities in access to or delivery of services
- high costs associated with accessing physical health services
- limited availability of services and barriers to access
- limited consideration of environmental support requirements
- limited opportunities for autistic people or families to find out information or engage in informed decision-making
- limited or inconsistent delivery of services that are tailored to individual needs and preferences.

Table 1.8 ranks the seven issues raised regarding autistic people's experience with physical health services. The issues are listed from most frequently raised to least frequently raised overall.

Table 1.8: Most frequently reported issues in relation to autistic people's experience with physical health services

Rank	Issue raised in submission that relates to autistic people's experiences with physical health services	Quote(s) to reflect lived/ living experience	% of submissions coded to this issue (overall) Total *N* = 1,575	% of submissions coded to issue				
				Senate Select Committee Total (*N* = 153)	NAS Submissions Total (*N* = 54)	Parliament of WA Inquiry Total (*N* = 77)	NAS Discussion Boards Total (*N* = 273)	Autism CRC Reports Total (*N* = 1,018)
1	**A lack of autism awareness, understanding, and/or training among physical health professionals, including knowledge of autism's heterogeneity and associated needs** (e.g., physical health professionals do not recognise how autistic traits present differently across individuals or know how to adapt assessment and treatment approaches accordingly)	*"It should also be mandated that every health professional needs to be educated on Autistic people, by Autistic people. If a health professional does not understand what Autism is or how Autistic people communicate it significantly impacts the quality of healthcare that the Autistic person receives."* (ID 1696; 20-year-old autistic woman living in regional Queensland; NAS Submission) *"In healthcare settings, I have had had severe chronic illness and autoimmune conditions overlooked because I have been unable to explain my symptoms in ways that are expected."* (ID 1746; autistic woman; Senate Select Committee)	33.3%	18.3%	38.9%	1.3%	5.1%	45.2%

Rank	Issue raised in submission that relates to autistic people's experiences with physical health services	Quote(s) to reflect lived/ living experience	% of submissions coded to this issue (overall) Total *N* = 1,575	% of submissions coded to issue				
				Senate Select Committee Total (*N* = 153)	NAS Submissions Total (*N* = 54)	Parliament of WA Inquiry Total (*N* = 77)	NAS Discussion Boards Total (*N* = 273)	Autism CRC Reports Total (*N* = 1,018)
2	**Limited consideration of environmental support requirements** (e.g., lack of physical accessibility, absence of sensory-friendly spaces, or inadequate accommodations)	*"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."* (ID 3495; autistic community and other stakeholder group; Autism CRC Report) *"The physical environment of healthcare settings can be difficult to navigate and can fuel anxiety that is already heightened. Clear signage and making information and maps available online ahead of time would ease some of the mental load. More attention also needs to be given to the sensory impact of such things as harsh lighting and loud conversations."* (ID 1729; late diagnosed autistic, ADHD, LGBTQIA+ mother; NAS Submission)	23.7%	2.0%	11.1%	2.6%	1.5%	35.2%
3	**Limited availability of services and barriers to access** (e.g., lack of physical health support, long waitlists)	*"Increase access and availability of reproductive and sexual healthcare services for people with autism, particularly in regional and remote areas."* (ID 335; reproductive and sexual health organisation; Senate Select Submission) *"Long waiting lists to access physical health services."* (ID 3493; autistic community and other stakeholder group; Autism CRC Report)	15.5%	8.5%	1.9%	3.9%	1.1%	22.0%

Rank	Issue raised in submission that relates to autistic people's experiences with physical health services	Quote(s) to reflect lived/ living experience	% of submissions coded to this issue (overall) Total *N* = 1,575	% of submissions coded to issue				
				Senate Select Committee Total (*N* = 153)	NAS Submissions Total (*N* = 54)	Parliament of WA Inquiry Total (*N* = 77)	NAS Discussion Boards Total (*N* = 273)	Autism CRC Reports Total (*N* = 1,018)
4	**High costs associated with accessing physical health services** (e.g., expensive therapy sessions, assessment fees, or ongoing treatment costs)	*"Services are too expensive to access."* (ID 3499; autistic community and other stakeholder group; Autism CRC Report) *"Bulk billing for Autistic people. A lot of us struggle financially, and getting to the doctor in the first place is a huge effort itself let alone the costs associated with the appointments."* (ID 3369; autistic person; NAS Discussion Board)	10.2%	2.6%	0.0%	0.0%	1.8%	14.9%
5	**Limited or inconsistent delivery of services that are tailored to individual needs and preferences** (e.g., services not adapted to the individual's sensory, communication, or cognitive needs, or lack of individualised support plans)	*"Setting up more Speech-Language Pathologists will not help if the programs are not required to take on board the students with the greatest needs. When we were rejected from [program], we were told it was because [child] needs were too high. So effectively the very program that was set up for kids like [child] is not available to [child]."* (ID 2253; parent of an autistic son; Parliament of WA Inquiry) *"We recommend the higher vulnerability to gastrointestinal and respiratory issues among autistic cohorts are areas of concern for which specific tailored health care responses should be developed to mitigate risk."* (ID 1162; university; Senate Select Committee)	10.1%	19.0%	7.4%	6.5%	2.2%	11.3%

Rank	Issue raised in submission that relates to autistic people's experiences with physical health services	Quote(s) to reflect lived/ living experience	% of submissions coded to this issue (overall) Total *N* = 1,575	% of submissions coded to issue				
				Senate Select Committee Total (*N* = 153)	NAS Submissions Total (*N* = 54)	Parliament of WA Inquiry Total (*N* = 77)	NAS Discussion Boards Total (*N* = 273)	Autism CRC Reports Total (*N* = 1,018)
6	**Limited opportunities for autistic people or families to find out information or engage in informed decision-making** (e.g., lack of clear information about service options)	*"Ability for practitioners to identify on platforms like HealthEngine if they offer neuro-affirming practices."* (ID 3297; autistic person; NAS Discussion Board) *"Finding information about the available services is a challenge."* (ID 3396; autistic community and other stakeholder group; Autism CRC Report)	4.3%	4.6%	1.9%	0.0%	1.5%	5.5%
7	**Gender-based inequities in access to or delivery of services** (e.g., differences in service availability or support provided to individuals across all gender identities)	*"There is NO support service for autistic adults where I live but females in particular are discriminated against on the grounds they do not present with the same traits as males. There needs to be more focus on informing the medical community that autistic females exist, that we will present differently in diagnostic criteria and we will reacted totally differently to treatment both medication based and therapeutic."* (ID 116; autistic female; Senate Select Committee) *"Medical misogyny is pervasive in the health sector, which leads to autistic women being gas lit and invalidated in the health system."* (ID 1953; organisation for autistic women and gender diverse individuals; NAS Submission)	0.5%	2.0%	9.3%	0.0%	0.0%	0.0%

1.5.2.8 Mental health services

In total, 1,422 issues related to mental health services were reported, making up 13.1% of total issues raised. It was the 4th most frequently reported domain. The issues raised within this domain were coded into the following nine issues:

- a lack of autism awareness, understanding, and/or training among mental health professionals, including knowledge of autism's heterogeneity and associated needs
- gender-based inequities in access to or delivery of services
- high costs associated with accessing mental health services
- interventions that are inappropriate or harmful
- limited access to recreational facilities and social support groups
- limited availability of services and barriers to access
- limited consideration of environmental support requirements
- limited or inconsistent delivery of services that are tailored to individual needs and preferences
- limited opportunities for autistic people or their families to engage in informed decision-making.

Table 1.9 ranks the nine issues raised regarding autistic people's experience with mental health services. The issues are listed from most frequently raised to least frequently raised overall.

Table 1.9: Most frequently reported issues in relation to autistic people's experience with mental health services

Rank	Issue raised in submission that relates to autistic people's experiences with mental health services	Quote(s) to reflect lived/ living experience	% of submissions coded to this issue (overall) Total *N* = 1,575	% of submissions coded to issue				
				Senate Select Committee Total (*N* = 153)	NAS Submissions Total (*N* = 54)	Parliament of WA Inquiry Total (*N* = 77)	NAS Discussion Boards Total (*N* = 273)	Autism CRC Reports Total (*N* = 1,018)
1	**A lack of autism awareness, understanding, and/or training among mental health professionals, including knowledge of autism's heterogeneity and associated needs** (e.g., mental health professionals do not recognise how autistic traits present differently across individuals or know how to adapt assessment and treatment approaches accordingly)	*"Mental health services need to be better resourced and educated to support people with autism, improve autism recognition and understanding, together with improved service coordination and collaboration across sectors."* (ID 1194; peak body for social workers; Senate Select Committee) *"I would like to see medical professionals in the field of psychology and medicine, particularly emergency, general practice and psychiatry, to be required to have specialist training as part of recognised training and as part of ongoing Continuing Professional Development in order to be qualified to treat patients with autism."* (ID 1885; 21-year-old autistic woman; NAS Submission)	37.7%	16.3%	42.6%	0.0%	9.5%	51.0%
2	**Limited availability of services and barriers to access** (e.g., hard to get referral, lack of mental health support, long waitlists)	*"Long wait lists for psychology and mental health supports and lack of in-patient mental health beds."* (ID 2069; organisation; NAS Submission) *"Improve access of autistic adolescents and adults to community-based mental health services."* (ID 1507; peak autism service and support provider; Senate Select Submission)	21.0%	14.4%	20.4%	1.3%	5.9%	27.6%

Rank	Issue raised in submission that relates to autistic people's experiences with mental health services	Quote(s) to reflect lived/ living experience	% of submissions coded to this issue (overall) Total *N* = 1,575	% of submissions coded to issue				
				Senate Select Committee Total (*N* = 153)	NAS Submissions Total (*N* = 54)	Parliament of WA Inquiry Total (*N* = 77)	NAS Discussion Boards Total (*N* = 273)	Autism CRC Reports Total (*N* = 1,018)
3	**High costs associated with accessing mental health services** (e.g., expensive therapy sessions, assessment fees, or ongoing treatment costs)	*"Access and affordability problems with psychology need to be addressed."* (ID 3362; late diagnosed autistic and ADHD woman; NAS Discussion Board)	10.6%	3.3%	9.3%	0.0%	3.3%	14.5%
4	**Interventions are inappropriate or harmful** (e.g., strategies or treatments used may not suit the individual's needs and can cause harm, i.e., medications, electroconvulsive therapy)	*"Psycho-tropic medication for children, teenagers and adults with ASD should be outlawed without a formal secondary diagnosis of mental illness specifically requiring that treatment."* (ID 1796; demographics not stated; NAS Submission) *"The second issue I would like to draw attention to is the widespread use of medication as a frontline treatment for behavioural difficulties in young people with ASD, before other non-pharmacological interventions have been tried."* (ID 317; clinical psychologist; Senate Select Committee)	9.9%	5.9%	18.5%	13.0%	2.9%	11.7%

Rank	Issue raised in submission that relates to autistic people's experiences with mental health services	Quote(s) to reflect lived/ living experience	% of submissions coded to this issue (overall) Total *N* = 1,575	% of submissions coded to issue				
				Senate Select Committee Total (*N* = 153)	NAS Submissions Total (*N* = 54)	Parliament of WA Inquiry Total (*N* = 77)	NAS Discussion Boards Total (*N* = 273)	Autism CRC Reports Total (*N* = 1,018)
5	**Limited or inconsistent delivery of services that are tailored to individual needs and preferences** (e.g., services not adapted to the individual's sensory, communication, or cognitive needs, or lack of individualised support plans)	*"People with autism who also have mental health issues are sometimes detained in adult mental health facilities which are inappropriate for people with autism. Their mental health needs need to be managed by taking into considerations the effect autism may have on the treatment and management of the individual."* (ID 501; autism education and awareness organisation; Senate Select Committee) *"Specialised psychologists for Autism, ideally those who also identify as Autistic."* (ID 3110; late diagnosed autistic and ADHD woman; NAS Discussion Board)	4.9%	17.0%	13.9%	0.0%	2.6%	3.6%
6	**Limited access to recreational facilities and social support groups** (e.g., sports clubs, community centres, peer support groups)	*"We need more groups for Autistics to connect with other Autistics, more recreational activities based on our interests."* (ID 2820; autistic person; NAS Discussion Board) *"Due to the high prevalence of discrimination against Autistic people and of experiences of isolation within the Autistic community, it is even more important to maximise the benefits of peer networks as a valuable source of friendship, peer support, and representative advocacy. These peer networks may also take the form of shared special interest spaces."* (ID 2017; disability, injury, or illness organisation; NAS Submission)	2.3%	7.8%	13.0%	1.3%	5.9%	0.0%

Rank	Issue raised in submission that relates to autistic people's experiences with mental health services	Quote(s) to reflect lived/ living experience	% of submissions coded to this issue (overall) Total *N* = 1,575	% of submissions coded to issue				
				Senate Select Committee Total (*N* = 153)	NAS Submissions Total (*N* = 54)	Parliament of WA Inquiry Total (*N* = 77)	NAS Discussion Boards Total (*N* = 273)	Autism CRC Reports Total (*N* = 1,018)
7	**Limited opportunities for autistic people or their families to engage in informed decision-making** (e.g., lack of clear information about service options)	*"Information is currently fragmented and there needs to be an easily accessible central point for people to obtain information specifically in relation to autism and mental health, including where to access services and supports and which practitioners specialise in this area."* (ID 831; hospital; Senate Select Committee) *"Provide resources to educate and support families and caregivers to make safe and informed decisions regarding [mental health] care."* (ID 1330; psychology professional body; Senate Select Committee)	2.2%	3.9%	5.6%	0.0%	0.0%	2.6%
8	**Limited consideration of environmental support requirements** (e.g., lack of physical accessibility, absence of sensory-friendly spaces, or inadequate accommodations)	*"Having properly funded, specialised sub sections of psychiatric inpatient wards in public and private hospitals which are allocated to the neurodiverse population. This might include having rooms which have dimmed lights, or are more soundproof, and single occupant only."* (ID 1714; self-diagnosed autistic queer woman with chronic mental health and pain conditions; NAS Submission) *"Mental health services need additional support to ensure services have appropriate spaces to meet the cognitive, sensory, social and communication preferences of autistic young people."* (ID 1878; early intervention mental health service; NAS Submission)	0.9%	3.3%	13.0%	0.0%	0.7%	0.0%

Rank	Issue raised in submission that relates to autistic people's experiences with mental health services	Quote(s) to reflect lived/ living experience	% of submissions coded to this issue (overall) Total *N* = 1,575	% of submissions coded to issue				
				Senate Select Committee Total (*N* = 153)	NAS Submissions Total (*N* = 54)	Parliament of WA Inquiry Total (*N* = 77)	NAS Discussion Boards Total (*N* = 273)	Autism CRC Reports Total (*N* = 1,018)
9	**Gender-based inequities in access to or delivery of services** (e.g., differences in service availability or support provided to individuals across all gender identities)	*"Need for supporting the mental health and wellbeing of autistic women and gender diverse people across the lifespan. This includes understanding their experiences of mental health, misdiagnosis, autistic burnout, meltdowns and shutdowns."* (ID 1841; autistic women and gender-diverse people; NAS Submission) *"Because I am a well-presented articulate (masking) woman, I feel professionals often ignore my requests for mental health support as they don't see the struggling person I am when I am at home or other settings."* (ID 3365; late diagnosed autistic and ADHD woman; NAS Discussion Board)	0.8%	4.6%	5.6%	0.0%	1.1%	0.0%

1.5.2.9 Other issues raised in submissions

Overall, 1,421 issues were reported that did not exclusively fit into one of the domains that were used for coding. Therefore, some issues raised were placed into an 'other' domain. The 'other' domain made up 13.1% of total issues raised and was the 5th most frequently reported domain. The issues raised within this domain were coded into the following 10 issues:

- a lack of research and evaluation
- a lack of resources for autistic adults and across the lifespan
- a lack of resources in regional, rural, and remote areas
- challenges related to government support and systems
- limited support services for families and carers
- intersectional barriers and issues
- lack of autistic-led advocacy or leadership
- limited inclusion and diversity
- limitations of the NDIS
- overemphasis on the medical model of disability.

Table 1.10 ranks the 10 other issues that autistic people raised in consultations. The issues are listed from most frequently raised to least frequently raised overall.

Table 1.10: Other emerging or cross-area issues from submissions

Rank	Other emerging or cross-area issues from submissions	Quote(s) to reflect lived/ living experience	% of submissions coded to this issue (overall) Total *N* = 1,575	% of submissions coded to issue				
				Senate Select Committee Total (*N* = 153)	NAS Submissions Total (*N* = 54)	Parliament of WA Inquiry Total (*N* = 77)	NAS Discussion Boards Total (*N* = 273)	Autism CRC Reports Total (*N* = 1,018)
1	**A lack of resources in regional, rural, and remote areas** (e.g., limited availability of specialised services, long travel distances, workforce shortages)	*"Lack of health professionals and services, and disparity based on location (i.e., regional and rural)."* (ID 3498; autistic community and other stakeholder group; Autism CRC Report) *"I have worked in every region across WA for 33 years – many remote, regional and metro scenarios – autism is the same in all areas. Only difference is, in regional and remote areas it often goes undiagnosed due to lack of practitioners and availability of assessment."* (ID 2604; demographics not stated; Parliament of WA Inquiry)	26.0%	8.5%	14.8%	7.8%	1.5%	37.2%
2	**Limitations of the NDIS** (e.g., inadequate funding, untrained staff, barriers to accessing appropriate support)	*"...there remain opportunities for improvement across the NDIS including better operationalisation of the significant crossover between health and disability which is required to improve the outcomes of the NDIS for participants."* (ID 206; psychiatry professional body; Senate Select Committee) *"Because I'm 'Level 1' ASD, I'm not eligible for NDIS."* (ID 2934; CALD autistic adult with a disabled child and autistic teenager; NAS Discussion Board)	18.3%	51.0%	33.3%	6.5%	16.5%	14.0%

Rank	Other emerging or cross-area issues from submissions	Quote(s) to reflect lived/ living experience	% of submissions coded to this issue (overall) Total *N* = 1,575	% of submissions coded to issue				
				Senate Select Committee Total (*N* = 153)	NAS Submissions Total (*N* = 54)	Parliament of WA Inquiry Total (*N* = 77)	NAS Discussion Boards Total (*N* = 273)	Autism CRC Reports Total (*N* = 1,018)
3	**Challenges related to government support and systems** (e.g., lack of coordination between agencies, limited financial assistance, inadequate funding)	*"Certain neuro-divergences like ADHD are not funded by the government, so there is no help for these children and their families."* (ID 2747; ADHD parent of autistic children with ADHD and PDA; Parliament of WA Inquiry) *"A huge burden for myself as a parent of a child with autism is moving from provider to provider, school, care, therapy, Dr and professional having to share the context and information on and on.... Where is the glue to join our systems of information sharing and contextualised knowledge about my child's needs, progress and goals? How can health, education, care and NDIS share information more smoothly (and securely obviously) so I don't have to be the constant middle messenger, triage and information sifter between parties?"* (ID 3189; parent of an autistic child; NAS Discussion Board)	12.6%	45.1%	22.2%	37.7%	13.2%	5.1%

Rank	Other emerging or cross-area issues from submissions	Quote(s) to reflect lived/ living experience	% of submissions coded to this issue (overall) Total *N* = 1,575	% of submissions coded to issue				
				Senate Select Committee Total (*N* = 153)	NAS Submissions Total (*N* = 54)	Parliament of WA Inquiry Total (*N* = 77)	NAS Discussion Boards Total (*N* = 273)	Autism CRC Reports Total (*N* = 1,018)
4	**Lack of autistic-led advocacy or leadership** (e.g., limited inclusion of autistic voices in decision-making, program design, and policy development)	*"Promoting autistic people into positions of leadership, and increase visibility by appointing autistic people to government advisory groups and boards, and by showcasing the achievements of autistic people in government publications and on social media would help improve the visibility of autistic people in our communities."* (ID 1931; organisational submission; NAS Submission) *"We are wanting a paradigm shift towards ND affirming services and information, led and run by Autistic or neurodiverse people."* (ID 2931; autistic adult; NAS Discussion Board)	6.9%	33.3%	51.9%	10.4%	7.7%	0.0%
5	**A lack of research and evaluation** (e.g., inadequate funding, limited knowledge base)	*"That the Select Committee undertake a review of international best practice in how to best support autistic people within mainstream health services, including reproductive health care and develop recommendations to improve outcomes."* (ID 1474; parent of an autistic child; Senate Select Committee) *"Australia urgently needs a platform that can deliver scaled clinical trials at a pace that lifts the evidence base of effective therapies and gives the community real answers about what works and why."* (ID 1203; neurodevelopment support and advocacy organisation; Senate Select Committee)	5.8%	42.5%	20.4%	10.4%	2.9%	0.0%

Rank	Other emerging or cross-area issues from submissions	Quote(s) to reflect lived/ living experience	% of submissions coded to this issue (overall) Total *N* = 1,575	% of submissions coded to issue				
				Senate Select Committee Total (*N* = 153)	NAS Submissions Total (*N* = 54)	Parliament of WA Inquiry Total (*N* = 77)	NAS Discussion Boards Total (*N* = 273)	Autism CRC Reports Total (*N* = 1,018)
6	**Overemphasis on the medical model of disability** (e.g., prioritising diagnosis and impairment over social, environmental, and systemic factors, leading to limited holistic support)	*"The strategy needs to be inclusive and should focus on what it can do to promote the strengths of neurodivergence and to have enabling pathways and supports rather than focussing on a deficit model that entrenches barriers and challenges."* (ID 1890; 18-year-old autistic woman; NAS Submission) *"There needs to be a commitment to systemic change (a move away from the medical to the social model of disability) viewed through an intersectional lens that puts people at the centre and takes a holistic, trauma-informed approach to both health and social services."* (ID 3154; demographics not stated; NAS Discussion Board)	5.8%	5.2%	38.9%	5.2%	7.3%	3.7%
7	**Limited inclusion and diversity** (e.g., reduced autonomy, weak cultural capability, experiences of exclusion or lack of belonging, stereotypical or biased media portrayals)	*"Autistic people are not included. Our community may have been successful in raising awareness of autism, but it is still not accepting. Much work needs to be done in order to call ourselves an inclusive society."* (ID 1418; peak body for social workers; Senate Select Committee) *"The autistic and neurodiversity inclusion efforts are lagging behind the race and gender discussions. This is a new frontier, so it will take time to catch up."* (ID 524; autistic employment initiative; Senate Select Committee)	5.0%	26.1%	26.0%	13.0%	5.1%	0.0%

Rank	Other emerging or cross-area issues from submissions	Quote(s) to reflect lived/ living experience	% of submissions coded to this issue (overall) Total *N* = 1,575	% of submissions coded to issue				
				Senate Select Committee Total (*N* = 153)	NAS Submissions Total (*N* = 54)	Parliament of WA Inquiry Total (*N* = 77)	NAS Discussion Boards Total (*N* = 273)	Autism CRC Reports Total (*N* = 1,018)
8	**A lack of resources for autistic adults and across the lifespan** (e.g., limited access to tailored services for adults, gaps in transition support, and inadequate lifelong care options)	*"Diagnostic funding should be available across the lifespan and not solely early intervention age groups."* (ID 1431; state government; Senate Select Committee) *"There are few services/groups available for autistic adults, and those that do exist are often held in spaces used for autistic children (e.g., toys and educational posters on the wall, child-proof gates and locked doors, etc.) which is infantilising and potentially triggering to trauma survivors."* (ID 3242; autistic adult; NAS Discussion Board)	3.5%	21.6%	14.8%	0.0%	5.1%	0.0%
9	**Limited support services for families and carers** (e.g. lack of respite, guidance or support for caregivers)	*"Increase the availability and quality of planned respite care for families living with autism, to help prevent carer fatigue that can lead to family breakdown and relinquishment."* (ID 1390; autism support service; Senate Select Committee) *"If my child gets to the point where he cannot attend school at all, which is a very real prospect over the next couple of years, I will have to give up work completely."* (ID 2582; parent of an autistic ADHD child; Parliament of WA Inquiry)	3.4%	20.9%	14.8%	6.5%	2.9%	0.0%

Rank	Other emerging or cross-area issues from submissions	Quote(s) to reflect lived/ living experience	% of submissions coded to this issue (overall) Total *N* = 1,575	% of submissions coded to issue				
				Senate Select Committee Total (*N* = 153)	NAS Submissions Total (*N* = 54)	Parliament of WA Inquiry Total (*N* = 77)	NAS Discussion Boards Total (*N* = 273)	Autism CRC Reports Total (*N* = 1,018)
10	**Intersectional barriers and issues** (e.g., challenges faced by LGBTQIA+ individuals, CALD communities, gender differences, and co-occurring mental health conditions)	*"Ethnic biases in Autism research and advocacy mean most adult CALD autistics remain undiagnosed and lack the information to make sense of their social differences or to self-advocate, with detrimental consequences."* (ID 1781; autistic immigrant and mother of two autistic children; NAS Submission) *"Race can have a huge impact on seeking a diagnosis in some cultures as it has the perception of shame for a child diagnosed; therefore impacting some races not to seek a diagnosis of autism. In Australia, many international visa holders do not seek a diagnosis either concerned that they will not achieve residency in Australia if a child is diagnosed with autism. These reasons do have a significant impact for the prevalence in some ethnicities."* (ID 2605; demographics not stated; Parliament of WA Inquiry)	3.1%	7.2%	44.4%	5.2%	3.3%	0.0%

1.6 Australian community issues: Summary and key takeaways

A total of 1,575 submissions were identified across the four public sources. Of those that reported demographics, most were made by parents, family members, or caregivers of autistic people (43%); 38% of submissions were made by somebody who disclosed they are autistic. As these were public submissions (where standardised demographic reporting is not required), detailed demographic information was rarely provided. For example, co-occurring conditions were mentioned in 2.4% of submissions, use of AAC in 2%, and non-speaking status in 0.06%. No submissions explicitly described very high or complex support needs. In addition, 1.3% of contributors identified as Aboriginal and/or Torres Strait Islander, and 5.7% identified as culturally and linguistically diverse.

These demographic patterns are important for interpretation. The issues identified reflect the perspectives of people and organisations who were able and willing to engage in public consultation processes and whose submissions or consultation responses were publicly available. They may underrepresent the priorities of individuals with very high support needs, non-speaking autistic people, First Nations communities, CALD/CALM groups, and those experiencing socioeconomic disadvantage. As such, this review provides insight into issues commonly articulated through public consultation processes, but should not be interpreted as a complete or fully representative account of all autistic people's experiences. Any decisions informed by this synthesis should therefore consider the likelihood of unmet or less visible needs among underrepresented groups and seek to gain the perspectives of these groups before decisions are made.

Across the 1,575 submissions, a total of 10,842 issues were raised. Education was the most frequently reported domain, accounting for 20.8% of all issues. This was followed by physical health (14.2%) and employment (13.6%).

Across all nine domains, the single most frequently reported issue was workplace exclusion (40.1% within the employment domain). The second, third, and fifth most commonly reported issues all reflected a lack of autism awareness across different sectors: mental health (37.7%), education (36.7%), and physical health (33.3%). The fourth and tenth most reported issues related to limited consideration of environmental support requirements in education (36.3%) and physical health services (23.7%), respectively.

It is important to note that frequency of reporting does not necessarily equate to impact, severity, or urgency. The issues identified here reflect the breadth of concerns raised by contributors, rather than a ranked or weighted list of priorities for action. Some less frequently reported issues may reflect significant unmet needs within underrepresented groups whose voices were less visible in the submissions; see Section 5 for a summary of this. As such, the issues identified should be interpreted as descriptive of a selection of community-reported concerns, rather than prescriptive or hierarchical.

1.7 Aotearoa New Zealand community issues

1.7.1 Overview

Autism-specific Aotearoa New Zealand government consultation did not occur between 2019 and 2025. The following broader disability consultation, which included the autistic and autism communities, occurred:

- 2020 Health and Disability System Review
- 2021–2022 Education Highest Needs Review
- 2024–2025 Disability Support Service Review
- 2025 Disability Strategy Refresh.

These reviews did not include publicly available autism-specific submissions. Therefore, to determine alignment between issues identified in Australian government autism consultation and Aotearoa New Zealand data, the Autism CRC funded project – How do we get Autism Support Right in Aotearoa New Zealand? was used.

The project was commissioned during the overhaul of Aotearoa New Zealand's health system and establishment of Whaikaha – the new Ministry of Disabled People. This, together with international moves to establish national autism strategies and legislation (such as the Australian National Autism Strategy), was deemed a good time to explore support for a similar move in Aotearoa New Zealand.

The project aimed to gain perspectives from autistic people, parents, professionals, family/whānau to:

1. Understand the nature of existing supports for autistic people, and
2. Provide suggestions for future approaches to autism support.

1.7.2 Method

Descriptive and qualitative findings from the published report were reviewed and coded into key themes for each of the domains: diagnosis, early intervention and supports, education, employment, housing and independent living, justice system, physical health services, and mental health services. Quotes to illustrate lived/living experience are reported for key themes. Quantitative participant-rated understanding and acceptance, overall experience, and priorities for future approaches are also reported for each of the domains.

1.7.3 Results

A total of 1,042 participants were surveyed.

1.7.3.1 Stage 1: Who contributed to the Aotearoa New Zealand data?

Table 1.11 outlines key demographic data from the Aotearoa New Zealand data. Approximately one third of participants were autistic, two thirds were parents, family members, or caregivers of autistic people, and just under half were professionals who support autistic people.

Table 1.11: Demographics from the project "How Do We Get Autism Support Right in Aotearoa New Zealand?" (N = 1,042)

Category	Identities/roles*	% of total contributors (N = 1,042)
Stakeholder group	Autistic individual	29.5%
	Parent, family member or caregiver of autistic people	73.2%
	Educational professional	12.3%
	Allied health professional	3.9%
	Mental health professional	10.7%
	Researcher/policymaker	2.9%
	Other professional/prefer not to say	14.1%
Gender Identity	Female	82.1%
	Male	13.2%
	Non-binary	3.6%
	Other/prefer not to say	2.11%
Age range (years)	18–24	6.6%
	25–34	17.2%
	35–44	29.9%
	45–54	23.4%
	55–64	11.6%
	65+	3.6%
	Prefer not to say	7.7%
Ethnicity**	Pākeha/New Zealand European/other European	84.9%
	Māori	11.6%
	Pacific Peoples	3.8%
	Other	11.6%

*Participants were able to select all identities and roles that applied to them; this means that percentages exceed 100%.

**Participants were able to select all ethnicities that applied to them; this means that percentages exceed 100%.

1.7.3.2 Stage 2: What did the Aotearoa New Zealand data report on?

Tables 1.12 to 1.20 outline key themes and participant ratings for each domain. Given differences in collection of community-identified issues between Australia and Aotearoa New Zealand, the limited Aotearoa New Zealand data, and the primary aim to determine alignment between community issues across countries, themes for the Aotearoa New Zealand data are not ranked. Quotes are provided where these are available in the published report that this data is drawn from and are reported under the area in which they are reported in the published report.

Table 1.12: Issues in relation to autistic people's experience with diagnosis

Issue raised in submission that relates to autistic people's experiences with diagnosis	Quote(s) to reflect lived/ living experience	Participant-rated bad/very bad overall experience
Late, delayed and fragmented diagnosis pathways	*"The pathway to service provision is unclear even to professionals, so how can we expect parents to navigate such a tangled path?" (Professional)*	• Early identification of autism: 40% • Assessment for children: 50% • Assessment for adults: 44%
High cost associated with private diagnosis (financial privilege)	*"Diagnosis has become a privilege". (Autistic adult)*	
Stereotyped and narrow diagnostic understanding as well as misdiagnosis and diagnostic confusion (especially for women, Māori and high-masking individuals)	*"Many think of autism as Dustin Hoffman in Rain Man". (Family/ whānau member)*	

Table 1.13: Issues in relation to autistic people's experience with early intervention or supports

Issue raised in submission that relates to autistic people's experiences with early intervention or supports	Quote(s) to reflect lived/ living experience	Participant-rated bad/very bad overall experience
Lack of access to support following early identification	*"New Zealand fundamentally does not believe in supporting autistic kids". (Autistic parent)*	• Therapy and support for children: 40%
Rigid eligibility criteria and crisis-based access results in lack of coordination and lack of needs-based support	*"I personally find my needs hard to meet with all the obstacles and complicated processes". (Autistic adult)* *"Rather than have our needs assessed and then matched to suitable supports, we are just assessed to see if we are eligible for any of the supports provided... if your needs are different then you are on your own". (Autistic parent)*	
Judgement and blame directed to parents	*"This is a lonely journey where it's in the too hard basket for everyone". (Non-autistic parent)*	

Table 1.14: Issues in relation to autistic people's experience with education

Issue raised in data that relates to autistic people's experiences with education	Quote(s) to reflect lived/ living experience	Participant-rated bad/very bad
Lack of autism understanding and training across educators and leadership	*"There appears to be little or no training for majority of workers around Autism understanding. Parents/caregivers or the individual are expected to educate many professionals". (Autistic adult)* *"I am constantly frustrated at the lack of support and funding for my own child and for the children I work with. We can't just blame teachers for not having enough understanding when we don't train, support, educate and resource them properly". (Non-autistic parent)*	Understanding and acceptance of autism by school professionals: • Teachers: 13% • Teacher aides/ education support: 13% • Specialist support at school: 13% • School leadership: 21%
Mainstream education environments are not autism inclusive (lack of sensory- and communication-accessible environments)	*"Years of battles to get any educational placement". (Autistic parent)* *"I believe the education system is failing our kids". (Non-autistic parent)*	Support in the classroom: • Primary/intermediate: 39% • Secondary: 30% • Tertiary: 14%
Systemic exclusion and unlawful disciplinary practices	*"Very, very difficult system with a lot of stress for families, having to take kids out of school early, standdowns for meltdowns, punishments for neurology". (Non-autistic parent)* *"The current MoE [Ministry of Education] systems appear to largely consist of shuffling you from one waiting list to another, until the kid ages out and is no longer their problem". (Autistic parent)*	
Severe funding and resourcing gaps including rigid eligibility criteria	*"I am constantly frustrated at the lack of support and funding for my own child and for the children I work with. We can't just blame teachers for not having enough understanding when we don't train, support, educate and resource them properly". (Non-autistic parent)*	

Table 1.15: Issues in relation to autistic people's experience with employment

Issue raised in submission that relates to autistic people's experiences with employment	Quote(s) to reflect lived/living experience	Participant-rated bad/very bad
Lack of inclusive practices and workplace accommodations	*"Autistic people should not have to hide who they are in order to obtain employment". (Non-autistic parent)*	Understanding and acceptance by professionals • Employers/ managers: 30% • Employment support services: 22% • Work and Income New Zealand: 35%
Inadequate employment support systems (employment support services; Work and Income)	*"[Work and Income has] zero understanding of how traumatising their offices are". (Family/ whānau member)*	Overall experience • Employers/ managers: 36% • Employment support services: 18% • Work and Income New Zealand: 32%
Employment exclusion and discrimination despite capability (pressure to mask)	*"Individuals that have the potential to be employed and live independently are in reality denied this opportunity". (Non-autistic parent)*	
Flow-on impacts on whānau and caregiver employment		

Table 1.16: Issues in relation to autistic people's experience with housing and independent living

Issue raised in submission that relates to autistic people's experiences with housing and independent living	Quote(s) to reflect lived/living experience	Participant-rated bad/very bad overall experience
Shortage of suitable housing options (choice and control)	*"The lack of … true options around housing, support, vocational choices mean that many autistic people are severely restricted in their rights to freedom of choice and to live meaningful lives". (Autistic adult)*	Housing 35%
Forced dependence on family		
Housing is a critical issue for autistic adults		

Table 1.17: Issues in relation to autistic people's experience within the justice system

Issue raised in submission that relates to autistic people's experiences with the justice system	Quote(s) to reflect lived/ living experience	Participant-rated bad/very bad
Lack of autism understanding and training among professionals in the justice system	*"Autism... should be compulsory learning for all Govt agencies involved in public service i.e.,police, teachers, nurses". (Professional)*	Understanding and acceptance by criminal justice professionals • Police: 22% • Legal: 24% Overall experience • Legal: 23%
Risk of harm from inadequately trained staff (e.g., masking, meltdowns, etc.)		

Table 1.18: Issues in relation to autistic people's experience with physical health services

Issue raised in submission that relates to autistic people's experiences with physical health services	Quote(s) to reflect lived/ living experience	Participant-rated bad/very bad
Lack of autism understanding and training among health professionals	*"Most clinicians in the public sector have a limited or surface level understanding of autism". (Professional)*	Understanding and acceptance by health professionals • General practitioners: 29% • Other health clinicians: 29% • ACC: 16% Overall experience • Healthcare services: 44%
Autistic people are not believed or taken seriously	*"It's hard to get help when people don't let me speak". (Autistic adult)* *"People have to fight to be believed". (Professional)*	
Clinical health settings are not autism inclusive (lack of sensory- and communication-accessible environments)	*"Pretty much every clinical setting is a sensory nightmare for autistic people". (Autistic parent)*	

Table 1.19: Issues in relation to autistic people's experience with mental health services

Issue raised in submission that relates to autistic people's experiences with mental health services	Quote(s) to reflect lived/ living experience	Participant-rated bad/very bad
Lack of autism understanding and training among mental health professionals	*"Most clinicians in the public sector have a limited or surface level understanding of autism". (Professional)*	Understanding and acceptance by mental health professionals • Mental health professionals: 24%
Lack of access to suitable mental health care	*"If we are not safe to be ourselves, our needs cannot be met". (Autistic adult)*	Overall experience • Access to mental health services: 60% • Access to suitable mental health services: 60%
Risk of harm from inadequately trained staff (e.g., masking, meltdowns, etc.)	*"Staff with no proper training or knowledge of Autism … end up causing more harm than good for the child and whānau". (Professional)*	
Lack of support for whānau and caregivers	*"If we are not safe to be ourselves, our needs cannot be met". (Autistic adult)*	

Table 1.20: Other emerging or cross-area themes

Issue raised in submission that relates to autistic people's experiences with mental health services	Quote(s) to reflect lived/ living experience	Participant-rated bad/very bad
Limitations of the Disability Support System (DSS)	*"Parents shouldn't have to continually jump through hoops to gain access to ... funding". (Professional)*	
A lack of resources in regional, rural, and remote areas		
Challenges related to government support and systems (lack of coordination, inadequate funding)	*"Coordination between the services is terrible and no one can agree on who does what". (Autistic adult)* *"It's like you have all these agencies working against each other rather than collaborating together". (Non-autistic parent)* *"The systems there to help us are ... hugely difficult to navigate. And help is not easy to find". (Autistic adult)*	Coordination of services: 50%
Lack of autistic-led advocacy or leadership	*"Autistic adults are the only adults with any right to speak on behalf of autistic people". (Autistic adult)*	
Lack of resources for autistic adults and across the lifespan (limited supports and transition supports, lifelong care)	*"There is nothing for adults. You're just left to suffer". (Autistic adult)*	Transition to adulthood: 32%
Intersectional barriers and issues	*"Māori have their own approach which works for Māori". (Non-autistic parent)* *"Until we get rid of laws and policies that see autism as a burden on society... we will still be ruled by the majority wanting the minority to be more like them". (Autistic adult)*	

1.7.4 Summary and key takeaways

Aotearoa New Zealand data showed alignment with issues raised in Australian consultation across each of the domains: diagnosis, early intervention and supports, education, employment, housing and independent living, justice system, physical health services, and mental health services. There was also alignment in other emerging or cross-domain themes, particularly related to government support.

Both Australian and Aotearoa New Zealand data highlight the following community-aligned issues:

- lack of autism understanding and training among professionals; a dominant, cross-sector issue
- delays, long-waitlists, and cost barriers across diagnosis and support services
- lack of sensory-friendly environments and services that are not designed to meet autistic needs
- autistic learners' experience of exclusion and inadequate support
- existing supports skewed to childhood, with major gaps for adults
- fragmented systems and poor cross-sector coordination.

Community issues between Australia and Aotearoa New Zealand differ in two key structural ways.

1. A national strategy. While Australian community issues derive primarily from consultation to inform development of the Australian National Autism Strategy, Aotearoa New Zealand does not have an autism strategy. The Aotearoa New Zealand data highlight a call for a move away from the general disability approach to a neurodivergence or autism-specific strategy and accountability.
2. Indigenous rights and cultural grounded governance: Aotearoa New Zealand data highlight Te Tiriti o Waitangi principles, Māori concepts (e.g., takiwātanga, a Te Reo Māori word for autism), and culturally responsive supports. On the other hand, Australian issues capture intersectionality and cultural identity but do not feature an equivalent rights-and-governance framework.

2. Australian and Aotearoa New Zealand autism research published 2023–2025

2.1 Context

Autism research in Australia and Aotearoa New Zealand has expanded in recent years. However, it remains unclear whether this growth has led to more meaningful research across a broad range of categories, and whether it is reflective of our growth in understanding of the diversity of the autistic population (Emerson et al., 2024). Understanding both what research is being conducted and whose experiences are represented within it is critical. The applicability of research findings depends on who is included, how participants are described, and whether diverse social, cultural, and support contexts are visible within the evidence base.

This review focuses on studies conducted between 2023 and 2025 in Australia and Aotearoa New Zealand. The aims were threefold:

1. to map the primary domains of published research
2. to examine the types (or roles) of participants represented in Australian and Aotearoa New Zealand studies, and
3. to analyse reporting practices of participant demographics across the studies.

The emphasis on reporting practices of demographic data (over the demographic data itself) is intentional. Demographic characteristics are often described inconsistently across studies, using varied terminology, categorisation, and levels of detail. Rather than synthesising participant demographics (which is methodologically constrained by this variability), this review evaluates the visibility of demographic characteristics within published research. This approach allows us to assess whose identities and contexts are explicitly recognised in the literature, and where reporting gaps may limit equity, interpretation, and policy relevance.

Reporting categories for participant characteristics were selected based on PROGRESS guidelines (O'Neill et al., 2014) and priority groups identified in the National Autism Strategy report (Commonwealth of Australia, Department of Social Services, 2024), ensuring alignment with national equity and inclusion objectives.

Combined, these analyses provide a structured overview of research focus, participant representation, and demographic reporting practices.

2.2 Method

A systematic review methodology was employed to identify Australian and Aotearoa New Zealand autism-related research published between 2023 and 2025. A systematic review summarises existing published literature and only involves analysis of publicly available studies. As it does not involve collecting new data from people, systematic reviews do not meet the National Statement definition of human research and do not require ethical review.

Searches were conducted across 23 academic databases to ensure breadth of search (see Figure 2.1 for database list). The search term was also intentionally broad (autis*) to maximise capture of relevant studies. Where possible, database filters were applied by author affiliation or study location to focus on Australian and Aotearoa New Zealand research.

Articles were included if they:

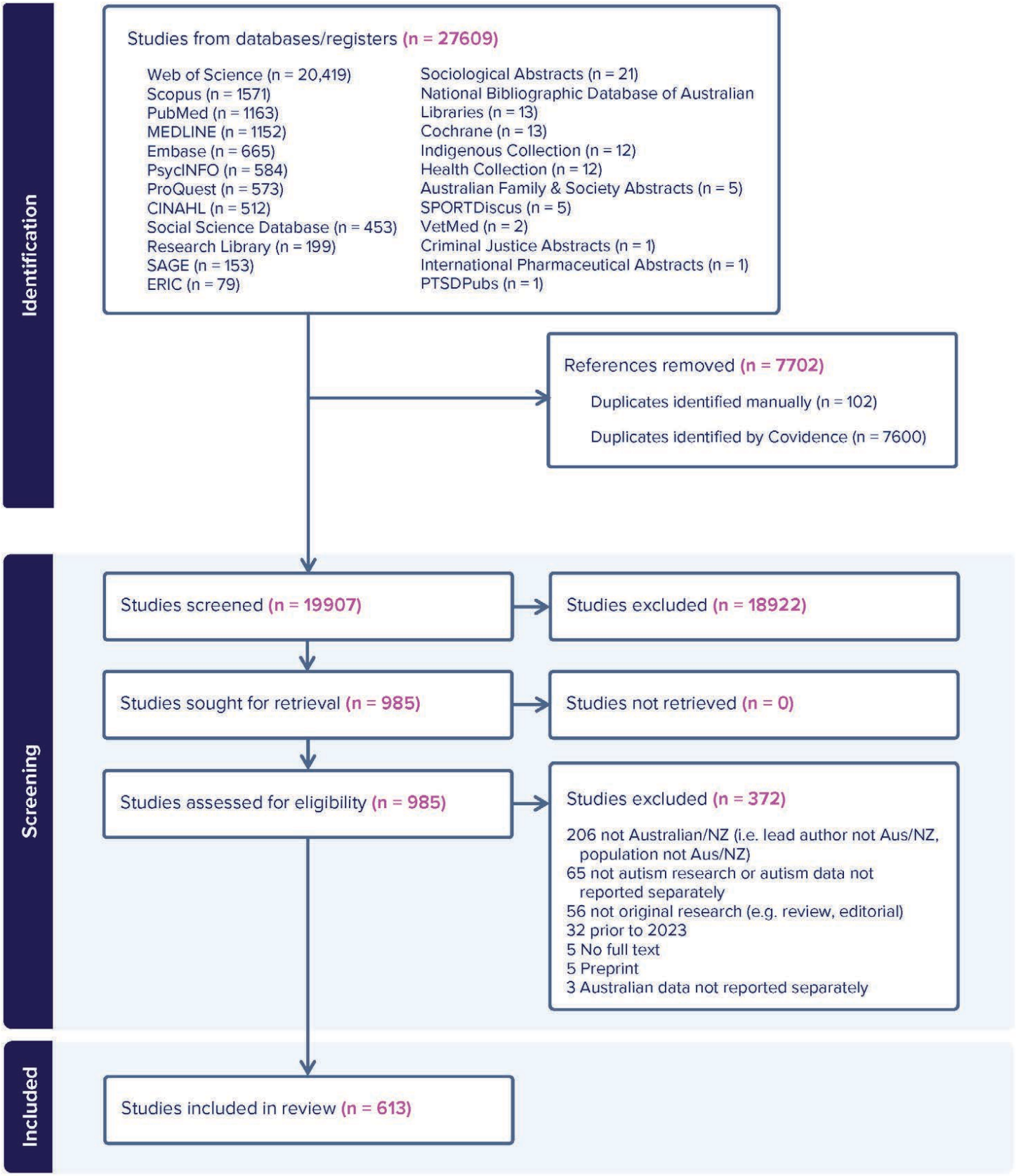
- focused on autism or autistic people, and
- had a lead author affiliated with an Australian or Aotearoa New Zealand institution or reported data specific to Australia or Aotearoa New Zealand that could be separated from multi-country datasets.

Figure 2.1 summarises the identification, screening, and inclusion of studies. The search identified 27,609 articles, of which 7,702 were duplicates, leaving 19,907 articles to screen at the title or abstract stage.

Each title and abstract was reviewed. Articles were excluded at this stage if they clearly indicated that data were collected outside Australia or Aotearoa New Zealand. In cases where study location could not be determined from the title or abstract (which comprised the majority of records) the affiliation of the first author was examined. Where the first author was affiliated with an Australian or Aotearoa New Zealand institution, the article proceeded to full-text review.

Full-text screening enabled confirmation of study location, identification of whether Australian or Aotearoa New Zealand data were reported, and extraction of information relating to research focus and participant characteristics.

Figure 2.1: PRISMA diagram of study identification, screening, and inclusion



2.2.1 Stage 1: Focus of published research articles (N = 613 studies)

Of the 613 articles, 510 were led by an author at an Australian institution and 103 by an author from an institution in Aotearoa New Zealand. All 613 studies were first categorised into the eight domains used throughout this report, based on the primary outcomes. These domains were purposefully aligned to those used to code the community issues in Section 1 to allow for direct comparison between community issues and research activity. However, it is important to note that many studies addressed multiple domains. Where no single domain clearly predominated, studies were classified under 'other emerging or cross-domain themes' to avoid artificially inflating counts in any one category. The topic of Basic Science was also added.

- Diagnosis
- Early intervention and supports
- Education
- Employment
- Housing and independent living
- Justice system
- Physical health services
- Mental health services
- Basic science
- Other emerging or cross-domain themes.

2.2.2 Stage 2: Participant characteristics in Australian and Aotearoa New Zealand research (N = 537 studies)

Stage 2 narrowed the focus to studies reporting data from Australian or Aotearoa New Zealand participants.

Of the 613 studies identified in Stage 1, 47 had a lead author affiliated with an Australian or Aotearoa New Zealand institution but reported data were not provided for Australian or New Zealand participants. A further 29 studies did not involve human participants and therefore yielded no extractable data. These studies were excluded at this stage because the focus here is on Australian and Aotearoa New Zealand participants only. This resulted in a sample of 537 studies for Stage 2 analysis.

For each of these 537 studies, information was extracted about:

- the type of data reported (e.g., genetic, human), and
- the role of participants (e.g., autistic child, autistic adult, parent/caregiver, professional).

2.2.3 Stage 3: Reporting of demographic characteristics (N = 383 studies)

As not all of the 537 studies reported data on autistic people (e.g., studies focused on parent wellbeing, healthcare providers' knowledge of autism), the sample was further refined at Stage 3 to include only those studies that reported demographic data on Australian or Aotearoa New Zealand autistic people (n = 383).

For these 383 studies, the reporting practices of participant demographics was examined. Specifically, information was extracted on whether and how studies reported:

- age
- sex and/or gender (including terminology used), and
- intersectional identities and/or co-occurring conditions, including
  - neurodevelopmental and health needs
  - cultural identity, and
  - geographic location.

Importantly, this analysis does not seek to aggregate or synthesise the demographic characteristics of participants across studies. Demographic variables were reported inconsistently in terminology, categorisation, and level of detail, making meaningful aggregation neither feasible nor methodologically sound. Instead, the focus was on how demographic information is reported within Australian and Aotearoa New Zealand autism research. Examining reporting practices allows assessment of the visibility of age, gender, neurodevelopmental and health needs, cultural identity, and geographic diversity within the published research. This is critical for understanding whose experiences are being made visible in research, whose may remain obscured, and how well the evidence base can inform equitable policy and service design.

2.3 Results

The staged approach allowed distinction among (1) the overall focus of published Australian and Aotearoa New Zealand autism research, (2) the participants most commonly represented within Australian and Aotearoa New Zealand research activity, and (3) the extent to which participant diversity is explicitly described in studies involving autistic participants. Each stage will be reported upon in turn.

2.3.1 Results of Stage 1: Focus of published research articles (N = 613 studies)

Included studies were categorised according to their primary research focus. Table 2.1 summarises the distribution across the domains.

Table 2.1: Focus of Australian and Aotearoa New Zealand research, 2023–2025, utilising predefined domains (Total N = 613 Studies)

Research area	Number of studies	%
Diagnosis	36	5.9%
Early intervention and supports	92	15.0%
Education	42	6.9%
Employment	16	2.6%
Housing and independent living	16	2.6%
Justice system	11	1.8%
Physical health services	44	7.2%
Mental health services	80	13.1%
Basic science	24	3.9%
Other emerging or cross-domain themes	252	41.1%

Across the 613 included studies, research activity was unevenly distributed across domains. Early intervention or supports represented the predefined domain with the largest proportion of articles (15.0%), followed by mental health services (13.1%), physical health services (7.2%), and education (6.9%). In contrast, comparatively few studies focused on employment (2.6%), housing and independent living (2.6%), or the justice system (1.8%). Basic science accounted for 3.9% of studies.

Notably, 41.1% of studies were categorised as 'other emerging or cross-domain themes'. These studies addressed multiple domains simultaneously or explored topics that did not align neatly with predefined policy-relevant domains. While this reflects conceptual complexity within autism research, it also indicates that a substantial proportion of research activity does not map cleanly onto service or systems domains raised in community consultations.

These patterns suggest that contemporary research focus (and potential investment) between 2023 and 2025 has been concentrated in early intervention or supports and mental health services, with comparatively limited attention to adult life domains such as employment, housing and independent living, and justice system involvement. This distribution provides an empirical basis for examining alignment with community-identified priorities and for identifying areas where lived or living experience concerns may not yet be proportionately reflected in published research.

2.3.2 Results of Stage 2: Participant characteristics in Australian and Aotearoa New Zealand research (N = 537 studies)

Participants are defined here as the people who provided the data reported in the study; for example, in studies involving autistic children, parents, family members, or caregivers often acted as participants/respondents. Some studies included more than one respondent type, hence the total number of studies across all participant types in Table 2.2 exceeds 537. Overall, the included studies drew on a range of participant types. Table 2.2 summarises the number of studies including each participant group.

Table 2.2: Participant types in Australian and Aotearoa New Zealand Autism Research, 2023–2025 (Total N = 537 studies)

Participant type (i.e., person who provided data or information on the autistic person)	**Number of studies**	%
Autistic people (self-reporting)	199	37.1
Parent, family member, or caregiver of autistic people	215	40.0
Educational professional	24	4.5
Clinician/professional	50	9.3
Employer	2	0.4
Other report (e.g., other informant, researcher observation)	86	16.0
Medical, physical or genetic measurements, or data from administrative records	80	14.9
Data from existing dataset	67	12.5

Across the 537 included studies, autistic people were informants in 37.1% of studies; parents, family members, or caregivers reported in 40.0%. Smaller proportions of studies reported data from other sources including educational professionals (4.5%) and employers (0.4%).

2.3.3 Results of Stage 3: Reporting of demographic characteristics (N = 383 studies)

This stage examined how demographic characteristics were reported in studies that included data on Australian or Aotearoa New Zealand autistic people (N = 383). Because demographics were reported in many different ways, the focus of this section was to report on the visibility and consistency of demographic reporting within the published research; in other words, what characteristics researchers chose to describe, and how they were categorised. The findings are summarised in Table 2.3.

Table 2.3: Reporting practices of demographics of autistic participants in Australian and Aotearoa New Zealand Autism research, 2023–2025 (Total N = 383 studies)

Category	Demographic characteristics	Number of studies reporting demographic information for autistic participants (Total 383)	%
Age	Age	264	68.9
Gender/sex	Reported as sex	84	21.9
	Reported as binary gender	113	29.5
	Reported both sex and gender	10	2.6
	Reported as gender identity (i.e., not as a binary variable)	102	26.6
	Not differentiated	66	17.2

Category	Demographic characteristics	Number of studies reporting demographic information for autistic participants (Total 383)	%
Co-occurring conditions and/or intersectional identities reported	LGBTQIA+	8	2.1
	Physical disability	25	6.5
	Intellectual disability	103	26.9
	Mental health diagnosis	135	35.2
	Augmentative and alternative communication (AAC) user, non-speaking or minimally speaking	42	11.0
	High or complex support needs	29	7.6
	Living in out of home care or supported accommodation	8	2.1
	Other neurodivergent diagnosis	143	37.3
Cultural identity	First Nations (Aboriginal and/or Torres Strait Islander, Māori)	63	16.4
	Culturally and linguistically diverse	42	11.0
Geographic location	Rural, regional, and remote	39	10.2

This review of how autism research reports on the demographics of Australian or Aotearoa New Zealand participants has shown that researchers are using varied and inconsistent ways to report demographics. It is interesting that only 68.9% of studies report the age of the autistic people reported on. This indicates that nearly one third of studies including autistic participants did not explicitly report participant age. Gender or sex of the autistic participants was reported in more studies than was age (80.6%), although how it was reported varied substantially in terminology and structure, with only 26.6% reporting gender identity beyond binary male-female categories.

Reporting of co-occurring conditions and intersectional identities was uneven across studies. Mental health diagnoses (35.2%), other neurodivergent diagnoses (37.3%), and intellectual disability (26.9%) were the most commonly reported characteristics. In contrast, fewer studies reported on whether or not participants used augmentative and alternative communication (11%), had high or complex support needs (7.6%), lived in out of home care/supported accommodation (2.1%), and identified as LGBTQIA+ (2.1%). Cultural identity was described in 11.0%–16.4% of studies, and geographic location (e.g., rural, regional, or remote residence) in 10.2% of studies. These figures suggest that while co-occurring neurodevelopmental and mental health conditions are relatively visible in the literature, other dimensions such as level of support required, communication profile, and sexual or gender diversity are less consistently reported. Given the known impact of these factors on service access and life outcomes, the relatively low reporting of these variables limits the capacity to assess equity and applicability of findings across diverse communities.

2.4 Summary

The findings from the three elements of this review provide a structured overview of the contemporary autism research landscape in Australia and Aotearoa New Zealand. It highlights two key findings.

First, research effort is concentrated in particular domains. Early intervention and supports and mental health services account for over a quarter of clearly defined research activity. In contrast, comparatively limited attention is directed toward adult life domains such as employment, housing and independent living, and justice system involvement. A large proportion of studies fall within cross-domain or emerging themes, reflecting conceptual breadth, but also limiting direct alignment with service and policy domains raised in community consultations.

Second, although over 500 studies reported Australian or Aotearoa New Zealand data, not all involved autistic participants. Of those that did, representation across life stage, support profile, cultural context, and geography cannot be assumed due to inconsistent (and often incomplete) demographic reporting. Key descriptors such as age, gender/sex, and certain co-occurring diagnoses are frequently, but not always, described. Other characteristics central to equity and service access, including cultural identity, geographic location, communication profile, support intensity, and LGBTQIA+ identity, are reported far less consistently. Variation in terminology and categorisation further complicates interpretation. Where demographic detail is limited or unevenly reported, it becomes difficult to assess whether research findings are applicable across diverse autistic communities.

3. Research priorities identified by the community

3.1 Overview

The following describes the process and outcomes of a systematic review of research outputs and reports of Australian and Aotearoa New Zealand autism research priorities.

3.2 Method

A systematic review summarises existing published literature and only involves analysis of publicly available studies. As it does not involve collecting new data from people, systematic reviews do not meet the National Statement definition of human research and do not require ethical review.

Search terms

Searches were undertaken in the ERIC, PsycInfo, PubMed, and DOAJ databases in October 2025 using the following terms: (priori* OR pref* OR stake-holder* OR autism community) AND (autism spectrum disorder* OR autis* OR asperger* OR asd OR pdd OR pervasive developmental disorder). Google searches were conducted with these terms to identify relevant grey literature for inclusion. Some grey literature was already known to the authors.

Inclusion and exclusion criteria

To be included, studies or reports (hereafter called studies) were required to meet the following predetermined inclusion criteria:

a. Studies must have focused on research priorities of key stakeholders of the autistic and autism community, including individuals with a diagnosis of autism, their family members, teachers, autism researchers, health professionals, and professional bodies.
b. Studies must have focused on the topic of autism, and while this could include a focus on co-occurring conditions associated with autism (such as ADHD), priorities for autism-related research need to have been reported separately.
c. Studies must have been published in peer-reviewed journals or by professional bodies.
d. Studies must have been conducted by authors in Australia or Aotearoa New Zealand.
e. Studies must have been published between 2019 and 2025.

Studies were excluded based on one or more of the following criteria:

a. Study priorities were for non-autism or mixed samples and the data for autistic individuals were not reported separately.
b. The study focused on those who were without a diagnosis, who were pre-diagnosis, or who had a self-identification of autism.
c. The study only reported on priorities for areas other than research (i.e., priority setting for healthcare policy).
d. The study was conducted by researchers outside of Australia or Aotearoa New Zealand.

3.3 Results

Electronic searches yielded 10,565 records following the removal of 2,021 duplicates. The initial screening identified 30 studies for full-text screening, of which four met inclusion criteria. There were a further four studies included from the Google search of grey literature, resulting in a total of eight studies being included in the final extraction and synthesis.

Participant and methodological characteristics were extracted and are presented in Table 3.1 and 3.2. Research priority areas were extracted and inductively categorised to facilitate comparison between studies and are presented in Table 3.3.

3.3.1 Participant and methodological characteristics

As summarised in Table 3.1, participants were recruited via social media in every study. Online advertisement and circulation through autism organisations, communities, and networks were also common. Less common recruitment methods included convenience sampling, advertisement at schools, and parent groups.

All studies employed online surveys. This includes questionnaires that collect quantitative and/or qualitative data. Five studies also included focus groups, and two also conducted semi-structured interviews. Most authors, regardless of background, were active autism researchers, with the exception of one study (AARC, 2020) which was conducted by a research consultancy group.

Table 3.1: Methodological characteristics of included studies

Study	Data collection method	Sampling technique	Country of participants
AARC, 2019	Online survey	Online advert	Australia
AARC, 2020	Focus group, Online survey	Online advert, EOI	Australia
AARC, 2023	Focus group, Online survey	Online advert circulated within community	Australia
Aspect, 2022	Focus group, Online survey	Social media, autism service organisations, schools and autism networks	Australia
Berry et al., 2025	Focus group, Online survey, Interviews	Social media, advisory group networks, autism organisations	Aotearoa New Zealand
Clark & Adams, 2020	Online survey, Q-Sort	Social media, community contacts, autism research groups	Australia
Emerson et al., 2024	Focus group, Online survey	Social media, practitioner networks, parent groups, schools	Aotearoa New Zealand
Grove et al., 2024	Interviews, Online survey	Social media, Australian disability and autism organisations	Australia

Across the eight included studies, there were a total of 2,519 participants. The largest proportion of these were family members of autistic individuals (48.83%), followed by autistic individuals (40.02%). There were relatively few participants who were professionals such as educators or educational professionals (2.22%), healthcare professionals (2.90%) or researchers (1.83%). Of the autistic participants, the majority were adults with only 122 (4.84% of all participants) being autistic youth. Most participants of studies reporting participant gender and age were women above the age of 30.

This suggests an increase in the representation of autistic participants in priority-setting research since the most recent review by Roche et al. (2020), who found that globally, only 9% of priority-setting research participants were autistic, none of whom were autistic youth. Moreover, none of the studies in Roche et al.'s review were conducted with exclusively autistic samples, whereas the present review found one recently published in Australia (Grove et al., 2024), and one recently published in Aotearoa New Zealand (Berry et al., 2025).

Table 3.2: Demographics of participants (and reporting practices for demographics) of Australia and New Zealand priority-setting studies

Demographic group	Contributor characteristics (where reported in submissions)	% of total participants (Total *N* = 2,519)	N studies	% of participants per study								% of participants, split by study methodology	
				AARC, 2019 (*N* = 1,102)	AARC, 2020 (*N* = 55)	AARC, 2023 (*N* = 73)	Aspect, 2022 (*N* = 172)	Berry et al., 2025 (*N* = 11)	Clark & Adams, 2020 (*N* = 143)	Emerson et al., 2024 (*N* = 505)	Grove et al., 2024 (*N* = 458)	Online Survey (*N* = 2299)	Focus Group/ Interview (*N* = 220)
Stakeholder group	Autistic individual	40.02%	7	22.41%	60%	54.79%	31.98%	100%	N/R	32.48%	100%	37.71%	34.01%
	Autistic adult	35.17%	6	22.41%	60%	54.79%	23.83%	0%	N/R	32.48%	78.82%	27.62%	26.82%
	Autistic child	4.84%	3	0%	0%	0%	8.14%	100%	0%	0%	21.18%	3.52%	7.27%
	Parent, family member or caregiver of autistic individual	48.83%	6	64.88%	91%	63.01%	36.63%	N/R	100%	42.18%	N/R	43.41%	26.81%
	Educational professional	2.22%	2	N/R	N/R	15.07%	N/R	N/R	N/R	8.91%	N/R	2.17%	5.45%
	Health professional	2.90%	1	N/R	N/R	15.07	N/R	N/R	N/R	12.28%	N/R	2.65%	3.18%
	Researcher	1.83%	3	N/R	32.73%	13.70%	N/R	N/R	N/R	3.56%	N/R	1.60%	2.72%
	Other professional	2.38%	2	N/R	N/R	8.22%	31.40%	N/R	N/R	N/R	N/R	< 1%	N/R
	Unspecified Other/Not reported	5.56%	1	12.70%	N/R	N/R	N/R	N/R	N/R	N/R	N/R	6.08%	N/R

Demographic group	Contributor characteristics (where reported in submissions)	% of total participants — Total *N* = 2,519	N studies	% of participants per study								% of participants, split by study methodology	
				AARC, 2019 (*N* = 1,102)	AARC, 2020 (*N* = 55)	AARC, 2023 (*N* = 73)	Aspect, 2022 (*N* = 172)	Berry et al., 2025 (*N* = 11)	Clark & Adams, 2020 (*N* = 143)	Emerson et al., 2024 (*N* = 505)	Grove et al., 2024 (*N* = 458)	Online Survey (*N* = 2299)	Focus Group/ Interview (*N* = 220)
Gender identity	Female	72.13%	6	83.30%	N/R	35.62%	N/R	18.19%	97.90%	74.06%	77.95%	71.03%	45.91%
	Male	9.21%	6	12.34%	N/R	2.74%	N/R	72.73%	2.10%	16.44%	0%	9.22%	5.45%
	Non-binary gender	6.98%	6	3.35%	N/R	2.74%	N/R	9.10%	0%	6.93%	22.05%	7.05%	5.91%
	Gender not reported	1.13%	2	0%	N/R	38.9%	N/R	0%	0%	0%	0%	12.72%	42.73%
Self-reported co-occurring conditions and/or intersectional identities	LGBTQIA+	7.60%	1	N/R[b]	N/R	16%	N/R	N/R[b]	N/R	N/R[b]	N/R[b]	N/R[b]	N/R[b]
	Mental health condition[a]	33.59%	2	40.11%	N/R	N/R	N/R	N/R	N/R	N/R	88.21%	35.14%	17.27%
	Physical disability	12.58%	2	9.98%	N/R	17.81%	N/R	N/R	N/R	N/R	42.35%	13.79%	12.72%
	Intellectual disability	0.87%	3	1.18%	N/R	N/R	N/R	N/R	N/R	N/R	1.96%	< 1%	1%
	Augmentative and alternative communication (AAC) user	0.12%	1	N/R	N/R	4.11%	N/R	N/R	N/R	N/R	N/R	< 1%	N/R
	Non-speaking	0.36%	3	N/R	5.46%	N/R	N/R	N/R	N/R	N/R	1.31%	< 1%	N/R

Demographic group	Contributor characteristics (where reported in submissions)	% of total participants — Total *N* = 2,519	N studies	% of participants per study								% of participants, split by study methodology	
				AARC, 2019 (*N* = 1,102)	AARC, 2020 (*N* = 55)	AARC, 2023 (*N* = 73)	Aspect, 2022 (*N* = 172)	Berry et al., 2025 (*N* = 11)	Clark & Adams, 2020 (*N* = 143)	Emerson et al., 2024 (*N* = 505)	Grove et al., 2024 (*N* = 458)	Online Survey (*N* = 2299)	Focus Group/ Interview (*N* = 220)
Employment & education	Employed	40.21%	2	69.87%	N/R	N/R	N/R	N/R	N/R	N/R	53.06%	33.49%	10%
	Student	9.13%	2	12.06%	N/R	N/R	N/R	N/R	N/R	N/R	21.18%	5.78%	7.27%
	Completed tertiary education	12.54%	2	N/R	N/R	N/R	N/R	N/R	82.51%	N/R	43.23%	5.13%	9.09%
Cultural identity	Indigenous people (Including Aboriginal, Torres Strait Islander, and Māori people)	3.69%	4	2.09%	10.90	0%	N/R	27.27%	N/R	9.11%	3.28%	3.87%	2.72%
	Culturally or linguistically diverse	10.12%	3	15.06%	10.90	6.85%	N/R	9.09%	N/R	N/R	16.81%	10.70%	3.63%
Geographic location	Urban/city/metro	29.54%	2	64.61%	N/R	43.84%	N/R	N/R	N/R	N/R	N/R	32.36%	N/R
	Rural/regional	8.89%	2	19.42%	N/R	13.70%	N/R	N/R	N/R	N/R	N/R	9.74%	N/R
	Not reported	61.57%	6	15.97%	100%	42.46%	N/R	100%	100%	100%	100%	57.9%	100%

[a]Only one study (AARC, 2023) directly reported on LGBTQIA+ status; other studies with reported LGBTQIA+ participants had reported only on gender diversity. It is likely that the rates of LGBTQIA+ participants are underestimated here.

[b]Did not report beyond reporting gender diversity.

N/R = Not Reported. This was recorded where a study may have recruited participants of a demographic but did not report on it. Where it could be confirmed that no participants of a demographic were recruited, 0% was recorded instead.

3.3.2 Community input into research processes

There is growing recognition of the importance of participatory research methods in autism research, aligning with "nothing about us, without us". The majority of studies reported community input from autistic individuals through formal autistic advisory structures, or through co-production. Only Clark and Adams' (2020) study did not report on community involvement. The two main forms of community input are provided below.

Formal autistic advisory structures

Emerson et al. (2024) and Berry et al. (2025) included two advisory groups who met at key milestones to guide recruitment, measure design, data analysis, and interpretation. Feedback flowed from an autistic advisory group to a broader partnership advisory group who delivered advice to the project team.

Co-produced and autistic-led structures

Grove et al. (2024) was led by autistic women and gender diverse researchers who co-developed the study with a non-autistic researcher. Autistic researchers created data collection materials, conducted interviews, and were closely involved in data analysis and manuscript production. Aspect (2022) utilised a large steering committee of researchers, parents, and autistic individuals that informed all stages. Autistic researchers were also involved in recruitment, data collection, and analysis. The Australasian Autism Research Council (AARC), a group which includes autistic individuals, researchers, and other stakeholders, conducted AARC (2019). The AARC also commissioned and oversaw AARC (2020) and AARC (2023). AARC (2020) recruited an autistic researcher who developed research guides and tools, and conducted fieldwork, data analysis, and reporting. They also sought additional governance through Amaze for advice on best practices for methodology, data collection, and reporting of autism research priorities. AARC (2023) co-designed data collection materials with members of the autistic and autism community and involved the community in expounding study findings. They also sought input from autistic researchers and consultation with the AARC and Autism CRC to guide methodology and research focus.

3.3.3 Priorities across studies

Priorities reported across the studies are synthesised in two ways: inductively and deductively. Inductive coding allows overarching priority domains to emerge directly from the data, ensuring that the synthesis reflects how priorities are described across studies rather than being constrained by pre-existing categories. This approach captures nuance and permits identification of novel or evolving areas of importance. Deductive coding applies the eight predefined domains used to code the community issues to the extracted priorities. This enables easier comparison and synthesis between issues raised in community submissions and the research priorities identified in the literature, facilitating assessment of alignment and gaps between lived experience and research focus at the end of the report.

Summary of priorities identified inductively

The priorities reported in each study were reviewed and inductively coded into 10 categories. The specific priority topics are broken down by category and study in Table 3.3. It was not possible to explore priorities by stakeholder group in detail as most papers reported aggregated results.

Priorities within the inductive codes of Health and mental health and the Community acceptance, understanding, and inclusion category were the most consistently reported, present in seven out of the eight studies (87.5%). The second most frequently reported priority category was Supports and Services, and Education, both of which were identified in six studies (75%). Employment-related research was prioritised in five studies (62.5%), Independent and daily living, Support needs and Hearing lived experiences were all prioritised in four (50%) of studies. Priorities in the Social relationships category were identified in three studies (37.5%). Finally, priorities within the Family category were the least commonly reported, identified in only two studies (25%).

Table 3.3: Summary and frequency of inductively coded priority categories

Category	Freq-uency	Specific priorities within each category per study							
		AARC, 2019 Australia	**AARC, 2020 Australia**	**AARC, 2023 Australia**	**Aspect, 2022 NZ**	**Berry et al., 2025 Australia**	**Clark & Adams, 2020 Australia**	**Emerson et al., 2024 NZ**	**Grove et al., 2024 Australia**
Community acceptance, understanding and inclusion	7 (87.5%)	Raising awareness and educating the Australian community about autistic people	Awareness, understanding and attitudes; People, community, and prevalence	Awareness and under-standing of autism	Acceptance	Inclusion and equitable access; Public acceptance	Community awareness and understanding of autism; Inclusive activities and attitudes; Community attitudes; Awareness, understanding and acceptance of autism	-	Understanding the role of society, embracing neurodiversity and the importance of autistic identity
Health and mental health	7 (87.5%)	Health and wellbeing	-	Mental health	Mental health	Supports for mental health and wellbeing; Access to supports	Health and wellbeing	Health, mental health, and wellbeing of autistic people; QoL of autistic people in New Zealand	Autism-specific mental health support; Supporting mental health and wellbeing; Addressing barriers in healthcare; Understanding and supporting physical health needs

Category	Frequency	Specific priorities within each category per study							
		AARC, 2019 Australia	AARC, 2020 Australia	AARC, 2023 Australia	Aspect, 2022 NZ	Berry et al., 2025 Australia	Clark & Adams, 2020 Australia	Emerson et al., 2024 NZ	Grove et al., 2024 Australia
Supports and services	6 (75%)	-	Policy, practices, support and accommodation; Information, training and professional development	The NDIS	Support services	Access to services	Diagnosis, intervention and support	Expertise, coordination, availability, and accessibility of services across the lifespan; Culturally grounded supports; Training for professionals	-
Education	6 (75%)	Education	-	-	Education	Learning, education of teachers	School resources and support; Supporting diverse and individual learning needs; Teacher/staff education and support	Education/ School	Better understanding and support at school; Addressing barriers in education and the workplace
Employment	5 (62.5%)	Employment	-	Finances	Workplace	-	-	Workplace/ Employment	Addressing barriers in education and the workplace

Category	Frequency	Specific priorities within each category per study							
		AARC, 2019 Australia	AARC, 2020 Australia	AARC, 2023 Australia	Aspect, 2022 NZ	Berry et al., 2025 Australia	Clark & Adams, 2020 Australia	Emerson et al., 2024 NZ	Grove et al., 2024 Australia
Independent and daily living	4 (50%)	Communication	-	-	Adult life and the future; Self care	-	Self-care, daily living skills and independence; Behaviour and behaviour support; Emotions, regulation and behaviour	Supporting skills development from childhood into adulthood	-
Support needs	4 (50%)	-	-	Support needs	-	Supports	-	Needs of autistic people in New Zealand	Accommodations to make life easier for us; Understanding and supporting specific needs in adulthood

Category	Frequency	Specific priorities within each category per study							
		AARC, 2019 Australia	AARC, 2020 Australia	AARC, 2023 Australia	Aspect, 2022 NZ	Berry et al., 2025 Australia	Clark & Adams, 2020 Australia	Emerson et al., 2024 NZ	Grove et al., 2024 Australia
Hearing lived experiences	4 (50%)	-	Experiences, preferences and needs	-	-	The autistic experience	-	Perspectives from autistic people with a diverse range of support needs	Co-designing research and supports with autistic people; Experiences of gender diversity; Experiences of trauma, abuse, and sexual violence; Understanding our experiences, strengths and challenges
Social relationships	3 (37.5%)	-	-	-	Relation-ships	-	Socialisation and social support; Relationships (social and romantic) and support	-	Autistic friends and relationships
Family	2 (25%)	-	-	The role of family	-	-	Parent, sibling, child and family support	-	-

Note. Clark & Adams (2020) reported 15 ranked priorities across three separate domains (home, school, and community), for a total of 45 priorities. This is three times more than any other included study, which creates the risk of this sample overrepresenting the priorities. To avoid this, only the top 5 for each domain in Clark & Adams (2020) were extracted and included, for a total of 15 priorities. The ranks within each top 5 were not extracted.

Summary of priorities coded deductively (i.e.,into the predefined domains)

To facilitate synthesis with other reports on community raised issues and recently published autism literature in Australia, the priorities for each of the studies were coded into the eight domains of:

- diagnosis
- early intervention and supports
- education
- employment
- housing and independent living
- justice system
- physical health services
- mental health services.

It should be noted that the priorities reported within the studies did not neatly code into these eight domains, however, the use of 'other' was actively avoided in order for the results to be useful. This meant that many priorities had to be coded into a domain on the basis of:

a. conventional assumptions of where it could fit (e.g., coding NDIS into early intervention and supports)
b. the domain where it would have the greatest impact, or
c. stretched definitions of domains (e.g., stretching mental health to include things which indirectly improve autistic people's mental health, such as positive community attitudes).

Many priorities would comfortably fit into most of the eight domains, and as such each priority was coded in two ways: (a) coded conservatively, into the one best fitting domain; and (b) coded liberally, in up to three areas that were relevant. In Table 3.4, a code is used to show if the priority was coded into that domain because it was the most relevant (+; conservative coding) or in the top three domains that were relevant (O; liberal coding).

The relative frequency and proportions of priorities within each domain are reported in Table 3.4. Table 3.4 also shows which priorities were coded using conservative (i.e., one area per priority) or liberal (i.e., up to three areas per priority) coding.

No study covered all eight domains when priorities were coded conservatively, although Emerson et al. (2024), Grove et al. (2024), and Berry et al. (2025) did when priorities were coded liberally. The only domain that was unanimously covered, even with conservative coding of priorities, was education. Mental health and physical health were also both unanimously covered when coding was liberal and each covered in seven out of eight studies when coding was conservative. Employment was less common than other domains, appearing in five studies. The justice system was the least commonly covered domain, appearing in only three studies with conservative coding and in four studies with liberal coding. Employment was the only non-unanimous domain that did not get covered by additional studies when coding was liberal.

Table 3.4: Research priorities aligned to each domain within each study

Category	AARC, 2019 Australia	AARC, 2020 Australia	AARC, 2023 Australia	Aspect (2022) NZ	Berry et al, 2025 Australia	Clark & Adams, 2020 Australia	Emerson et al, 2024 NZ	Grove et al, 2024 Australia
Physical Health Services	+	+	+	o	o	+	+	+
Mental health services	o	+	+	+	+	+	+	+
Education	+	+	+	+	+	+	+	+
Justice system	+	–	–	–	o	–	+	+
Diagnosis	–	+	o	–	+	+	o	+
Early intervention and supports	+	o	+	o	+	+	+	o
Housing and independent living	–	o	o	+	+	+	o	+
Employment	–	–	+	+	+	–	+	+

+ Consersative coding: the best domain.

o Liberal coding: one of the top three domains.

– Not aligned in conservative or liberal coding.

3.4 Summary

Overall, among the inductively derived categories for Australian and Aotearoa New Zealand autism research there was a clear dominance of priorities categorised as (1) Community acceptance, understanding, and inclusion; (2) Health and mental health, (3) Services, and (4) Education. The ubiquity of these four categories suggests that the autistic and autism community has a pressing need for research to focus on topics that support autistic individuals' ability to healthily thrive within society, and that this should begin at a young age, even before autistic children access education. Future research in these areas will enable stronger community acceptance and inclusion, more adequate and equitable support for health and mental health, and increased accessibility of services that meet the support needs of autistic individuals.

Within deductively coded priorities, the domains most commonly identified as priorities were (1) Education; (2) Mental Health Services; (3) Physical Health Services; and (4) Early intervention and supports. This has a clear overlap with most of the top inductively derived categories. It is also notable that the only category which doesn't overlap directly is Community acceptance, understanding, and inclusion. While most of the predefined domains could contribute to inclusion and acceptance in some way, the absence of it as a domain suggests that the predefined priority domains may benefit from explicit recognition of the importance that acceptance, understanding, and inclusion have for the autistic and autism communities.

Across each of the included studies, there is also an overrepresentation of participants from White, Western, educated, and wealthy backgrounds, and of autistic adults relative to autistic youth. There is a notable absence of participants who identify as First Nations people, those who are non-speaking, and those from low-socioeconomic or culturally and linguistically diverse backgrounds. It is critical that future priority-setting research actively aims to include the perspectives of individuals from diverse and underserved populations such as these.

4. Australian and Aotearoa New Zealand autism research funding 2018–2025: A portfolio analysis

4.1 Context

The nature of autism research is, to a considerable extent, determined by the investment decisions of research funding bodies. Examining the landscape of autism research funding – what research is funded, by whom, and at what cost – can deliver insights into the priorities of researchers and funding bodies. By understanding whether and how these priorities align with or diverge from community priorities, valuable understanding can be gained, which can then be used to inform future investment decisions.

In the only portfolio analysis of Australian autism research funding to date, den Houting and Pellicano (2019) identified a considerable emphasis on investment in basic scientific research. Studies investigating the causes and biological underpinnings of autism was awarded 44% of all autism research funding in Australia across 2008–2017. Across the same period, research regarding services for autistic people received just 9% of funding, and research focused on autistic adults received only 5%. Emerson et al. (2023) identified a similar pattern of investment in Aotearoa New Zealand, with 67% of autism research funding across the period 2007–2021 allocated to biological research. These patterns are also consistent with broader global trends in autism research funding; analyses spanning the US, UK, and Canada have universally identified a high level of investment in basic scientific research (Harris et al., 2021).

This pattern of research funding allocation is poorly aligned with established community priorities for autism research. In Australia, Aotearoa New Zealand, and internationally, community consultations have consistently highlighted the need for applied research on topics including autistic health, mental health, and wellbeing; access to services; and support across the lifespan (Emerson et al., 2023; Roche et al., 2021). A systematic review of stakeholder perspectives on autism research priorities worldwide found that applied research was consistently prioritised over basic scientific research across all stakeholder groups and geographic locations (Roche et al., 2021). Pugsley et al.'s (2025) study into community attitudes towards autism genetics research identified that autistic community members harboured a deep sense of distrust of, and disappointment in, the research community, along with aspirations for research that "functionally and meaningfully embedded lived experience in the processes of knowledge generation about autism" (p. 10).

Recent developments in Australian autism research, policy, and practice, including the release of the Australia's first National Autism Strategy (Australian Government, 2025) and the NHMRC and ARC guidelines for community involvement in research (National Health and Medical Research Council & Consumers' Health Forum of Australia, 2026), signal a shift in institutional orientation to the autism community, with an increased focus on community engagement and self-determination. While it may be premature to expect to see the impact of these particular initiatives reflected in the patterns of research funding investment at this time, there has been mounting evidence of the misalignment between community priorities and those of funding bodies, which have served as a call for change over some years (den Houting & Pellicano, 2019; Emerson et al., 2023; Gatfield et al., 2016; Pellicano et al., 2013; Roche et al., 2021).

In this analysis, we examined autism research funding in Australia and Aotearoa New Zealand across the period 2018–2025. Specifically, the aim was to:

- Examine the distribution of Australian autism research funding across key research areas;
- Identify patterns of consistency and/or change in investment since the previous portfolio analysis; and
- Determine if and how patterns of autism research investment reflect autism community priorities.

4.2 Method

4.2.1 Funding searches

Grants eligible for inclusion in this analysis were those (a) awarded by a funding organisation in Australia or New Zealand; (b) conducted in Australia or New Zealand; (c) active at any time during the period 2018–2025; (d) for research with a specific focus on autism, and; (d) containing sufficient information for coding purposes.

Replicating the methods from den Houting and Pellicano's (2019) portfolio analysis, initial searches were conducted in Dimensions Plus (https://app.dimensions.ai). Search terms were updated to reflect learnings from the 2019 study and incorporate more contemporary terminology to capture all relevant data. The final search terms used were: autism OR ASD OR "Autism Spectrum Disorder" OR "Asperger Syndrome" OR Autistic OR neurodiv*. It should be noted that the criterion for active grants, consistent with previous portfolio analyses (e.g., Office of Autism Research Coordination, 2019), meant that the searches captured some grants that were awarded prior to 2018, creating some overlap with the data set used by den Houting and Pellicano (2019). Separate searches were conducted for Australia and Aotearoa New Zealand in order to limit results to grants awarded by local funders for research conducted in each country respectively.

Dimensions Plus is an expansive database of scholarly publications, datasets, research grants, patents, clinical trials, and policy documents. The majority of results returned by Dimensions were grants from major public funders, such as the ARC and NHMRC in Australia, and the Health Research Council and Royal Society of New Zealand. Searches were filtered to exclude results where the funder and/or the research location was outside of the target country.

In the interests of compiling an exhaustive data set, additional hand searches were undertaken of award lists published on the websites or in annual reports of known funders (including Autism CRC), published data from relevant government departments, and philanthropic entities. Where awards lists were not published on funders' websites, or lists were not comprehensive, a list of awarded grants was requested directly from the funder. Where grants identified did not have complete data, funding organisations and/or the recipient institution's research office were contacted to request or clarify missing information. Some, but not all, organisations provided full or partial information upon request. Finally, the search strategy for Dimensions was repeated in the Grant Connect database (https://www.grants.gov.au/). In Australia, most funding bodies are compelled by legislation to report their awards (Australian Research Council Act 2001 (Cth); National Health and Medical Research Council Act 1992 (Cth)). In New Zealand, funding bodies do not routinely publish investment outcomes; as a result, findings reported here may not constitute an exhaustive dataset of the country's autism research funding.

A notable exclusion from the dataset was a $45 million philanthropic bequest received by La Trobe University from the late Olga Tennison in 2022 (La Trobe University Media and Communications, 2022). While this bequest was a significant investment in autism research, it was excluded from the dataset as project level data were not available to support analyses.

All identified grants were screened by two researchers independently to establish whether each grant met the inclusion criteria, with particular attention to criterion (d) research with a specific focus on autism. They reached agreement on the research focus (i.e., autism-focussed versus not autism-focussed) of 96% and 100% for Australia and New Zealand respectively. Where there was disagreement, consensus was reached by discussion.

4.2.2 Coding and analyses

4.2.2.1 Coding framework

In the interests of consistency with previous portfolio analyses conducted in Australia (den Houting & Pellicano, 2019), Aotearoa New Zealand (Emerson et al., 2023), and in other parts of the world (Daniels et al., 2019; Harris et al., 2021; Office of Autism Research Coordination, 2012a, 2012b, 2016, 2017a, 2017b, 2019, n.d.), coding was undertaken using the research question framework outlined in the Interagency Autism Coordinating Committee (IACC) strategic plan (2017).

The IACC strategic plan was originally developed in 2009 to provide a comprehensive framework by which to track trends in autism research, identify gaps in scientific understanding, and guide future research (IACC, 2009). The IACC periodically releases updates to the strategic plan framework, the most recent of which was in 2023 (IACC, 2023). For this analysis, the researchers opted to use the 2017 iteration of the strategic plan, as this allows a direct comparison with the previous portfolio analyses.

A summary of the 2017 IACC strategic plan research questions and subcategories used in the coding process appears below in Table 4.1.

Table 4.1: IACC Strategic Plan research questions and subcategories (IACC, 2017).

2016–2017 IACC Research question	Subcategory
Screening and diagnosis – How can I recognise the signs of autism, and why is early detection so important?	• Diagnostic and screening tools • Early signs and biomarkers • Intermediate phenotypes/subgroups • Symptomatology
Biology – What is the biology underlying autism?	• Cognitive studies • Computational Science • Co-occurring conditions • Developmental Trajectory • Immune/metabolic pathways • Molecular pathways • Neural systems • Neuropathology • Subgroups/biosignatures
Causes – What causes autism, and can disabling aspects of autism be prevented or pre-empted?	• Environmental risk factors • Epigenetics • Gene-environment • Genetic risk factors
Treatments and interventions – Which treatments and interventions will help?	• Behavioural • Complementary, dietary, and alternative • Educational • Medical/pharmacologic • Model systems/therapeutic targets • Occupational, physical, and sensory-based therapies • Technology-based interventions and supports
Services – What kinds of services and supports are needed to maximise quality of life for people on the autism spectrum?	• Community inclusion programs • Efficacious and cost-effective service delivery • Family wellbeing and safety • Practitioner training • Service utilisation and access
Lifespan issues – How can we meet the needs of people on the autism spectrum as they progress into and through adulthood?	• N/A
Infrastructure and surveillance – How do we continue to build, expand, and enhance the infrastructure system to meet the needs of the autism community?	• Biobanks • Research infrastructure • Research recruitment and clinical care • Research workforce development • Surveillance and prevalence studies

Note: The IACC strategic plan did not specify subcategories for the "Lifespan issues" domain.

This analysis was conducted in parallel to the broader Mind the Gap project, which utilised identified domains to report on the current state of autism research in Australia and Aotearoa New Zealand. These domains can be loosely tracked to the IACC research questions, as shown in Table 4.2. A breakdown of funding allocation aligned with these domains is available in **5.1. Alignment of community issues, research priorities, research outputs and funding by domain** and **6. Alignment between autistic and autism community priorities and research activity: Aotearoa New Zealand**.

Table 4.2: IACC research questions aligned to Mind the Gap domains

2016–2017 IACC Research question	Subcategory
Diagnosis	• Screening and diagnosis
Early intervention and supports	• Treatments and interventions • Services
Education	• Treatments and interventions
Employment	• Lifespan issues
Housing and independent living	• Lifespan issues
Justice system	• Lifespan issues
Physical health services	• Biology • Services
Mental health services	• Biology • Services • Lifespan issues
Basic Science	• Biology • Risk factors

4.2.2.2 Coding and analyses

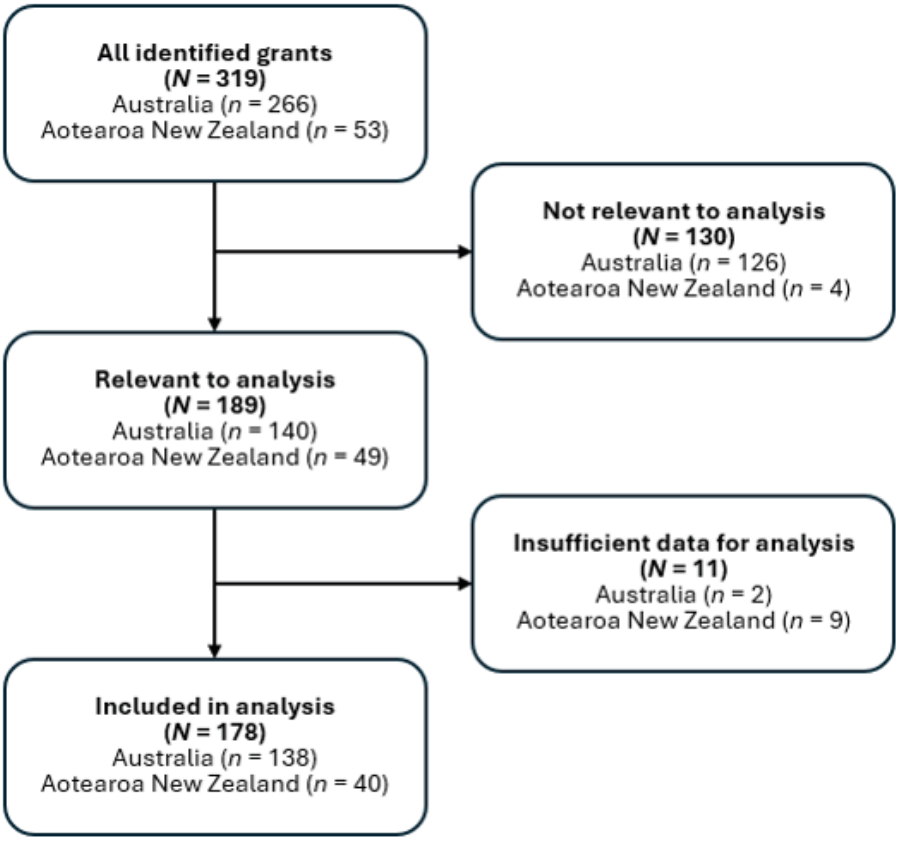
All included grants were blind coded by both researchers, with each grant coded to (a) one of the seven IACC research questions, and (b) one subcategory within the relevant research question. Coders reached agreement rates of 91% and 93% at the superordinate domain level (IACC research questions) for Australia and New Zealand datasets respectively. Agreement at the subcategory level was 80% (Australia) and 84% (New Zealand). In cases of disagreement, consensus was achieved through discussion. Three grants within the Aotearoa New Zealand dataset were coded as not aligning with any of the IACC research questions or subcategories. Due to the inclusion criterion for grants active from 2018–2025, there was some overlap with the dataset from the earlier portfolio analysis (den Houting & Pellicano, 2019) and original codes for these grants were carried over into the current dataset.

We conducted descriptive analyses to determine proportionate investment in autism research mapped with each of the IACC research questions. Figures cited in this chapter reflect only the cash investment aligned with each grant and in-kind contributions, where available, were not included.

4.3 Results

Initial searches returned a total of 319 grants, comprising 266 projects based in Australia and 53 in Aotearoa New Zealand (see Figure 4.1). Following dual-coder screening for relevance, 130 grants (Australia *n* = 126; Aotearoa New Zealand *n* = 4) were excluded from analyses. An additional 11 grants (Australia *n* = 2; Aotearoa New Zealand *n* = 9) were excluded as available data were insufficient to facilitate coding using the IACC framework (see Coding and Analyses). Grants from Aotearoa New Zealand are disproportionately represented in this figure owning to the heterogeneity of published awards data. A final total of 178 grants were included in analyses, comprising 138 projects based in Australia and 40 in Aotearoa New Zealand.

Figure 4.1: Grant screening process



4.3.1 How much money was invested in autism research?

From 2018 to 2025, just under AUD$81.7 million was invested across 138 autism research projects in Australia, and almost NZD$10.9 million was invested across 40 projects in Aotearoa New Zealand (Table 4.3). In Australia, the value of individual grants ranged from AUD$17,680 to AUD$3,762,327, with a median value of AUD$369,535. In Aotearoa New Zealand, individual grants ranged from NZD$1,210 to NZD$1,399,778, with a median value of NZD$159,375. Accounting for the current exchange rate , the median value of grants awarded in Aotearoa New Zealand was approximately one-third of that for Australia.

Table 4.3: Total autism research investment 2018–2025

Metric	Australia (AUD$)	Aotearoa New Zealand (NZD$)
Total investment	81,698,010	10,885,391
Project count	138	40
Mean (SD)	592,015 (733,232)	272,135 (340,018)
Median (IQR)	369,535 (107,204 - 679,706)	159,375 (30,000 - 295,523)

4.3.2 How is funding distributed across autism research topics?

In Australia, the greatest proportion of funding was invested in biological research, which received more than AUD$25 million between 2018–2025 and accounted for 34% of all autism research funding during this period (see Figure 4.2). This investment in biological research equates to almost double that awarded to the second-most funded topic, lifespan issues, which received approximately AUD$13 million and 16% of autism research funding. Autism research infrastructure and surveillance, and treatment and intervention research each received between AUD$10-11 million (13%), while research focused on screening and diagnosis, causes, and services each received approximately AUD$7 million (9%).

In Aotearoa New Zealand, biological research received approximately NZD$3.8 million between 2018–2025, representing 35% of the country's total autism research investment (see Figure 4.3). Treatment and intervention research, and research investigating services, each received approximately NZD$3 million, accounting for 31% and 27% of funding respectively. Approximately NZD$230,000 (2%) went to research investigating causes, and approximately NZD$75,000 (1%) was invested in infrastructure and surveillance. No research funding was invested in screening and diagnosis, or lifespan issues, in Aotearoa New Zealand during the study period. NZD$470,000 (8%) was invested in research that did not align with the IACC framework. This funding comprised three separate project grants, two of which focused on incorporating Indigenous knowledge to co-design culturally safe and neurodiversity-affirming supports for First Nations communities, while the third aimed to promote understanding and acceptance of autistic children within the general population.

It may be the case that different fields of research may require differing levels of investment per project; for example, some may argue that the basic sciences are inherently more resource intensive, thus, larger grants are required to undertake this research. To account for this possibility, we examined the number of grants awarded across research topics.

This approach to analyses revealed a similar pattern of investment in research. In Australia, 34 grants were awarded for biological research during the period 2018–2025, representing 25% of all funded autism research projects (see Figure 4.4). Thirty grants (22%) were awarded for research examining lifespan issues, 27 projects (20%) investigated treatment and interventions, and 21 grants (15%) were awarded for research regarding services. Screening and diagnosis, causes, and infrastructure and surveillance were each awarded 10 grants or fewer, accounting for 7%, 6%, and 6% of grants respectively.

In Aotearoa New Zealand, 16 grants awarded for biological research comprised 40% of all funded autism research projects (see Figure 4.5). Research regarding treatments and interventions, and services, each received 8 grants (20%). Four grants (10%) were awarded for research infrastructure and surveillance, and 1 grant (3%) went to research investigating causes of autism. As noted above, 3 grants (8%) did not align with the IACC framework.

Figure 4.2: Distribution of Australian autism research funding in AUD

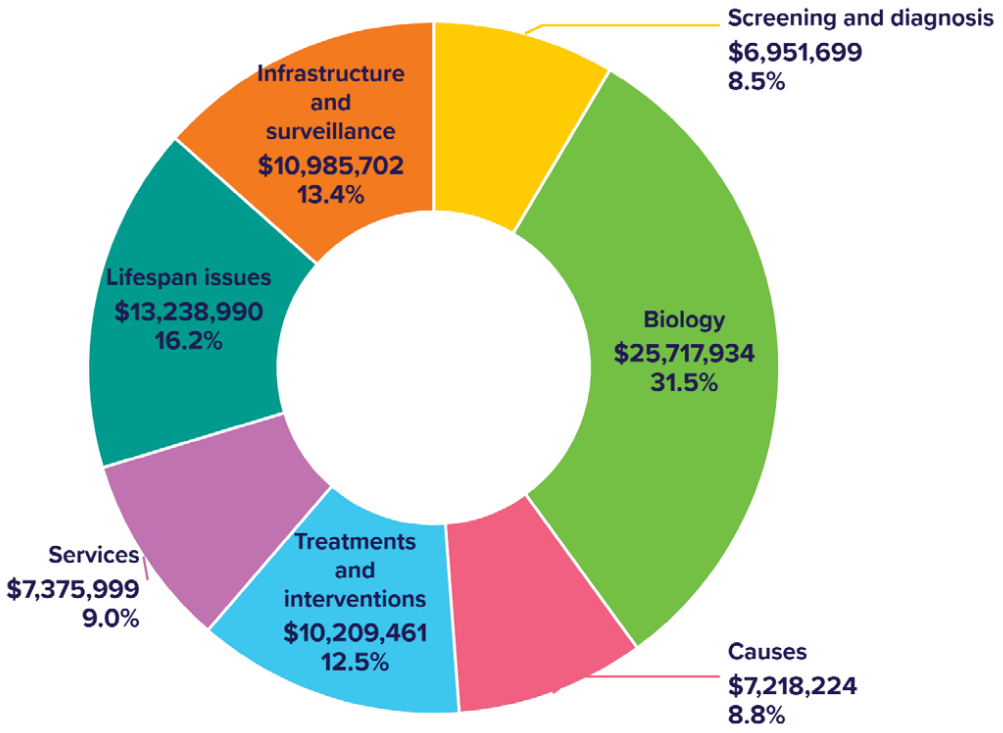


Figure 4.3: Distribution of Aotearoa New Zealand autism research funding in NZD

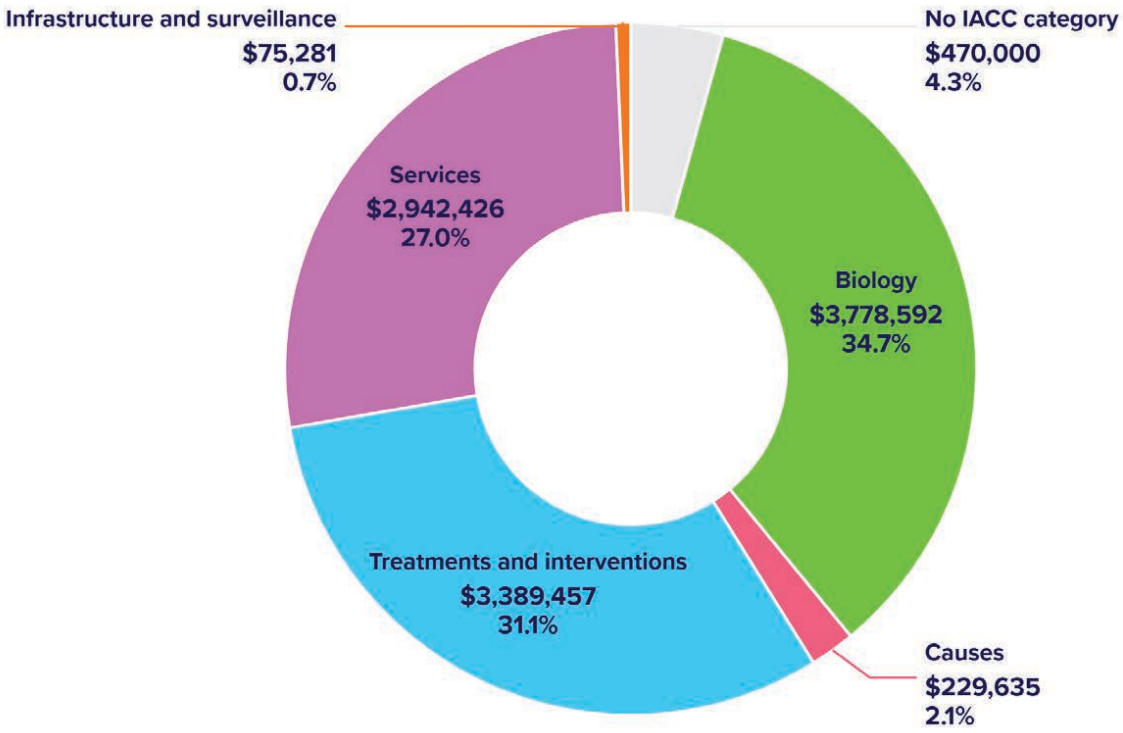


Figure 4.4: Distribution of Australian autism research funding by number of grants

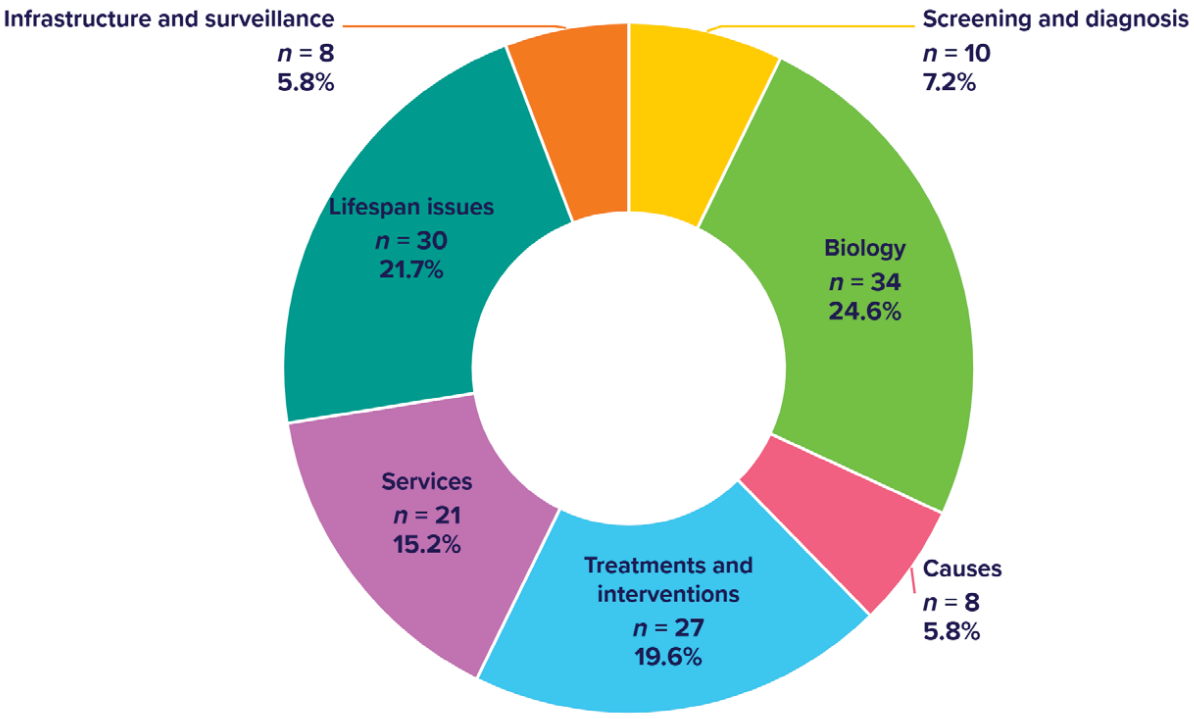
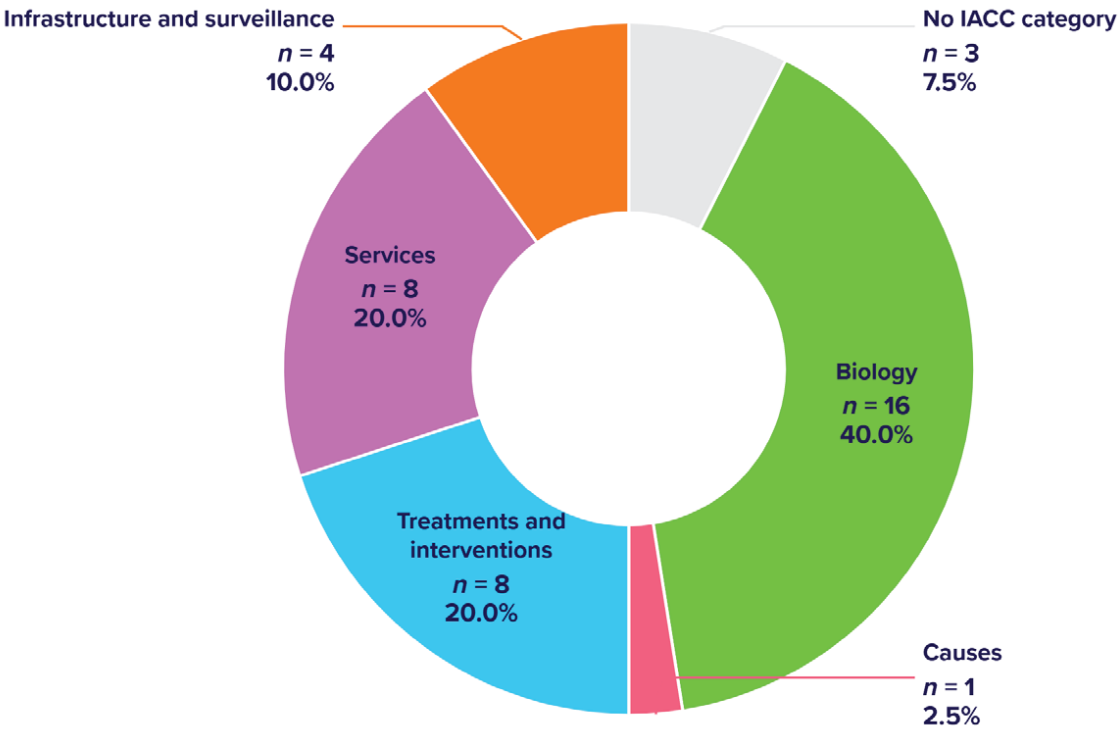


Figure 4.5: Distribution of Aotearoa autism research funding by number of grants



4.3.3 Who funds autism research?

In Australia, 94% of all autism research across 2018–2025 was funded by one of four major funding bodies (see Table 4.4). The National Health and Medical Research Council (NHMRC) made the largest financial investment in autism research, awarding more than AUD$37 million across 38 projects. With a total investment of almost AUD$21 million across 68 projects, Autism CRC funded almost half (49%) of all autism research projects active during the study period. Research funding bodies differed considerably in their patterns of investment across research topics (see Figure 4.6).

Table 4.4: Australian autism research investment by funding organisation, 2018–2025 (AUD$)

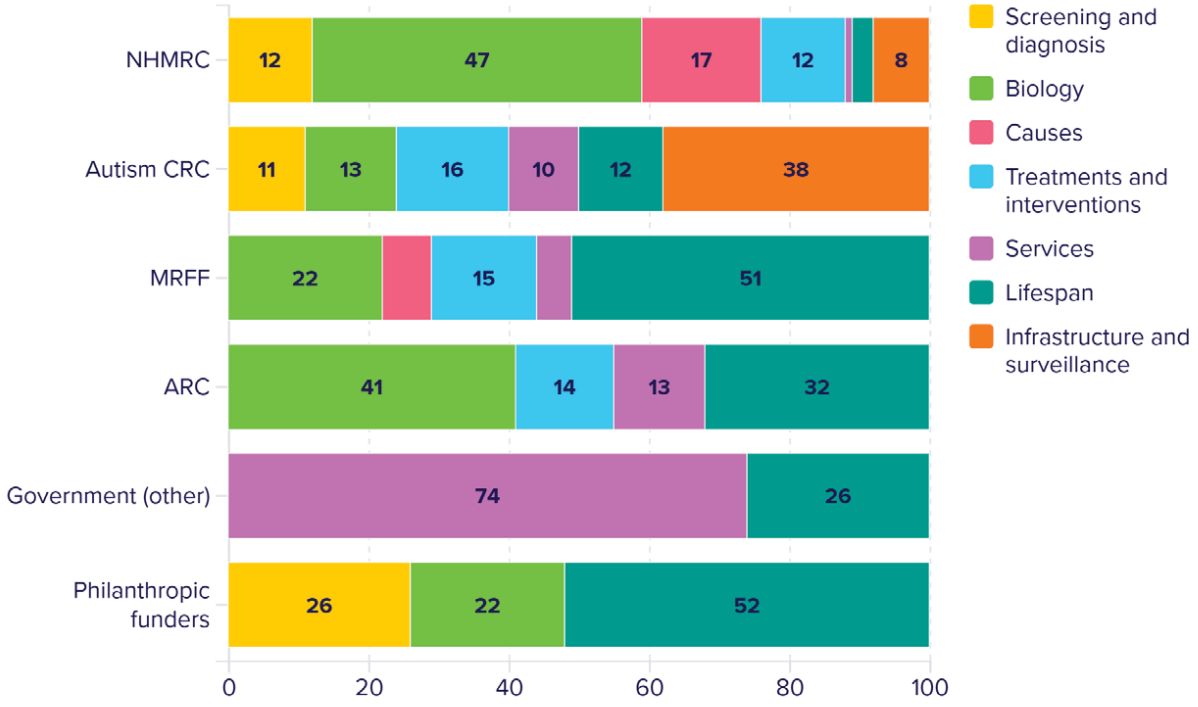
Funding organisation	Total investment	% of total funding	Project count	Mean per project (SD)	Median per project (IQR)
National Health and Medical Research Council (NHMRC)	37,387,452	46%	38	983,880 (819,360)	682,108 (470,144–1,237,870)
Autism CRC	20,939,070	26%	68	307,928 (513,819)	122,500 (50,000–318,893)
Medical Research Future Fund (MRFF)	11,117,434	14%	7	1,588,205 (1,196,270)	837,447 (748,010–2,500,000)
Australian Research Council (ARC)	6,960,312	9%	16	435,020 (123,766)	438,353 (359,448–521,548)
Other government agencies	4,709,734	6%	5	941,947 (832,958)	468,825 (397,426–1,744,494)
Philanthropic organisations	584,008	1%	4	146,002 (12,495)	151,292 (140,004–152,000)

Research funding bodies differed considerably in their patterns of investment across research topics (see Figure 4.6). Of the NHMRC's total investment in autism research, almost half (47%) funded biological research; a further 17% was awarded for research investigating causes of autism. Collectively, projects across these two research topics were awarded just under AUD$24 million, accounting for almost two-thirds (64%) of all autism research funding awarded by the NHMRC. Similarly, the Australian Research Council (ARC) directed the greatest proportion of their autism research investment to biological studies, with 41% of ARC funding awarded to this topic. In contrast, just over half (51%) of autism research funding awarded by the Medical Research Future Fund (MRFF) went to projects examining lifespan issues; this topic also received the second-greatest proportion of the ARC's investment, accounting for 32% of ARC autism research funding.

Of the total funding awarded by Autism CRC, 38% was invested to support research infrastructure and surveillance. The remainder of Autism CRC's investment was distributed roughly equally across all other research topics (with proportions ranging from 10-16% of total Autism CRC expenditure), with the exception of research investigating causes of autism, which did not attract Autism CRC funds.

Almost three-quarters (74%) of funding from other government sources was directed to research regarding services; this investment was comprised entirely of funding granted under the auspices of the Information, Linkages and Capacity Building (ILC) Program.

Figure 4.6: Distribution of Australian autism research funding across research topics, by funding organisation (%)



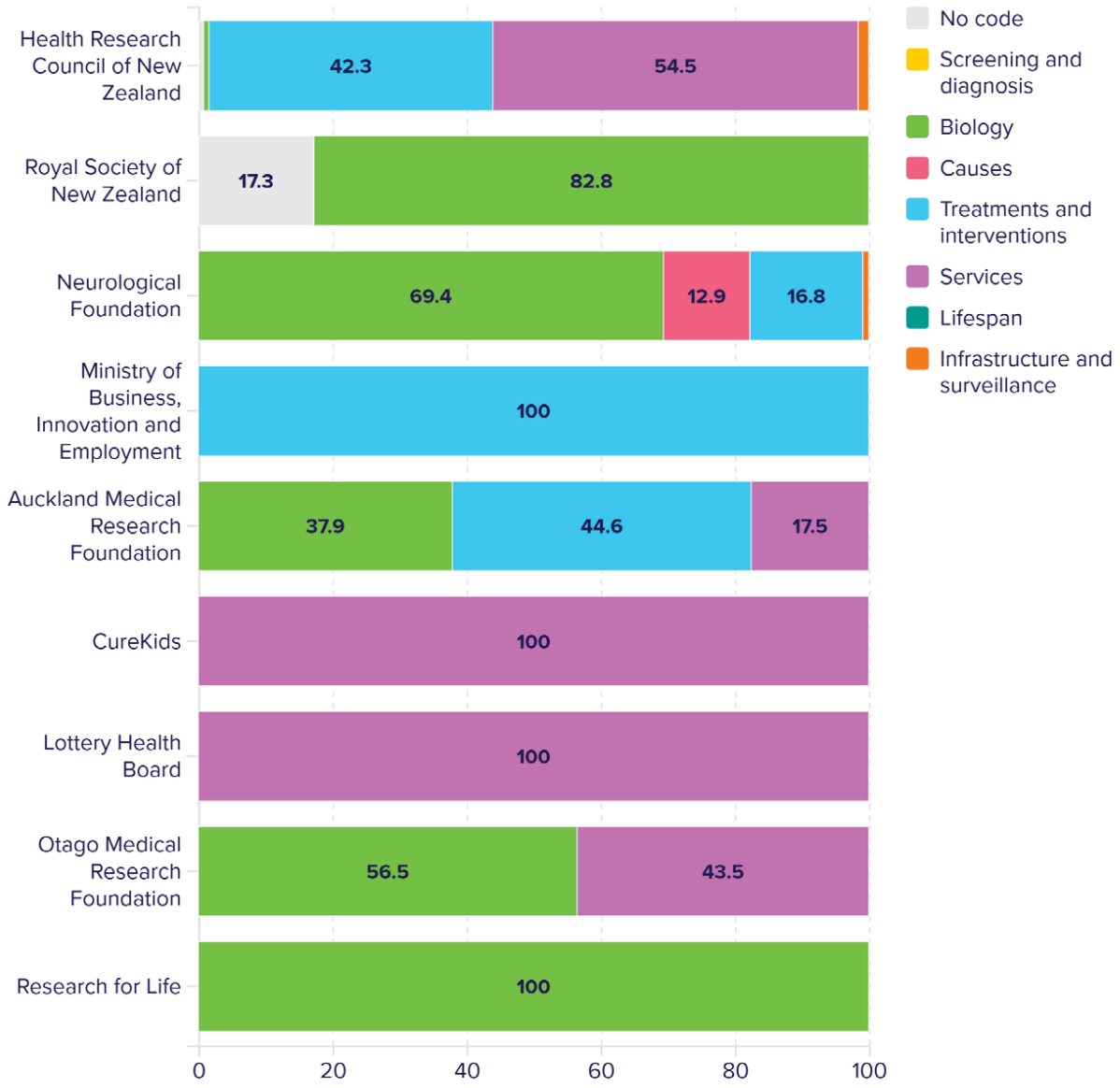
Across 2018–2025 in Aotearoa New Zealand, autism research grants were awarded by nine funding organisations (see Table 4.5). Akin to Australia, 93% of all autism research in Aotearoa New Zealand across the study period was funded by one of five organisations. The greatest financial investment came from the Health Research Council of New Zealand, which awarded NZD$3.7 million across 10 research projects.

In Aotearoa New Zealand, funding bodies' patterns of investment across research topics were relatively consistent (see Figure 4.7). Just over half (54%) of funding awarded by the country's largest autism research funder, the Health Research Council of New Zealand, was invested in research regarding services. The majority of remaining funding awarded by the five largest contributors was directed to biological research, and research investigating treatments and interventions. Aotearoa New Zealand's two smallest autism research funders also granted funds primarily for biological research, while the remaining two funding bodies invested exclusively in research regarding services.

Table 4.5: Aotearoa New Zealand autism research investment by funding organisation, 2018–2025 (NZD)

Funding organisation	Total investment	% of total funding	Project count	Mean per project (SD)
Health Research Council of New Zealand	3,731,578	34.3%	10	373,158 (498,720)
Royal Society of New Zealand	2,551,000	23.4%	5	510,200 (376,451)
Neurological Foundation	1,780,477	16.4%	11	161,862 (116,010)
Ministry of Business, Innovation and Employment	1,105,412	10.2%	1	1,105,412
Auckland Medical Research Foundation	909,378	8.4%	6	151,563 (74,070)
CureKids	624,382	5.7%	2	312,191
Lottery Health Board	99,966	0.9%	1	99,966
Otago Medical Research Foundation	58,198	0.5%	2	29,099
Research for Life	25,000	0.2%	2	12,500

Figure 4.7: Distribution of Aotearoa New Zealand autism research funding across research topics, by funding organisation (%)



4.3.4 Who receives funding for autism research?

In Australia, 25 institutions were awarded funding for autism research during the period 2018–2025; of these, 18 institutions received funds totalling more than AUD$1 million (see Table 4.6). A considerable proportion of funding was concentrated amongst a small number of recipient organisations; collectively, the three most-funded institutions received in excess of AUD$31 million, constituting just under 40% of Australia's total autism research funding.

Table 4.6: Australian autism research funding recipient institutions (> $1m), 2018–2025 (AUD) (sorted from highest funding received to lowest)

Recipient institution	Total funding received	Project count
University of Queensland	12,417,449	18
University of Western Australia	9,609,511	11
University of Melbourne	9,565,802	7
Curtin University	5,760,527	11
Monash University	5,034,610	3
University of Sydney	5,006,943	8
University of New South Wales	4,966,173	12
La Trobe University[2]	4,442,004	11
Deakin University	3,638,347	4
Queensland University of Technology	3,425,051	13
Alfred Health	2,300,191	1
Griffith University	2,293,160	7
Murdoch Children's Research Institute	1,931,372	6
Macquarie University	1,540,739	6
Australian National University	1,523,956	2
QIMR Berghofer Medical Research Institute	1,523,438	1
Florey Institute of Neuroscience and Mental Health	1,307,613	2
Southern Cross University	1,188,797	1

[2]As previously noted, La Trobe University received a philanthropic bequest of $45m during the timeframe of this analysis that is not reflected in these figures.

In Aotearoa New Zealand, five institutions were awarded funding for autism research during the study period (see Table 4.7). Of these five, four recipient organisations were universities, each of which received funds totalling more than NZD$1 million.

Table 4.7: Aotearoa New Zealand autism research funding recipient institutions, 2018–2025 (NZD)

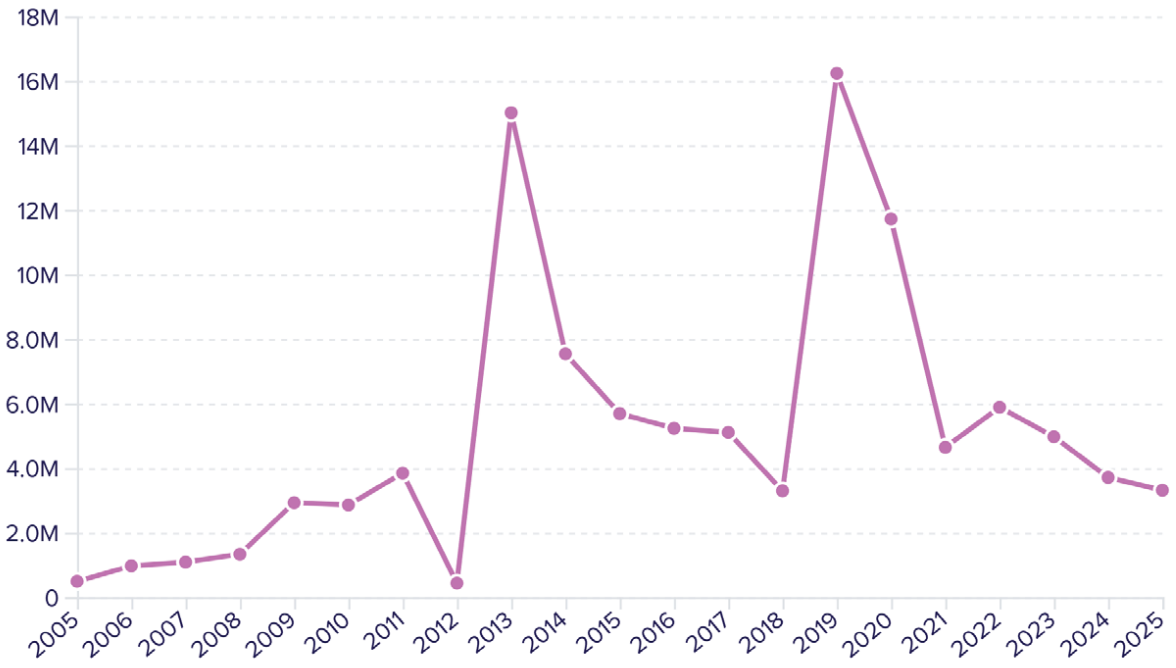
Recipient institution	Total funding received	Project count
University of Auckland	3,667,488	15
University of Canterbury	3,294,993	6
University of Otago	1,926,757	9
Victoria University of Wellington	1,766,518	9
Starship Child Health	229,635	1

4.3.5 Has the pattern of autism research funding changed over time?

To examine trends in autism research funding across time, data from the current analyses were combined with those from the previous Australian portfolio analysis (den Houting & Pellicano, 2019). The resulting data set represents all autism research funded in Australia across the period 2008–2025. As no data were available regarding autism research funding in Aotearoa New Zealand prior to the current study period, subsequent analyses are based on Australian data only. In all subsequent analyses, funding is reported based on grants awarded each year (rather than grants active each year).

As shown in Figure 4.8, Australian investment in autism research varied dramatically across time. Median annual investment across the study period was $4,807,679 (IQR $3,294916 – $5,886,714). Notable deviations occurred in 2013 and 2019, with funding awarded in those years totalling more than AUD$15 million and AUD$16 million respectively, each equating to more than triple the annual median. Similarly, almost AUD$12 million was granted in 2020, equating to more than double the annual median. In contrast, 2012 funding awards totalled less than $440,000, equating to less than 10% of the annual median investment in autism research.

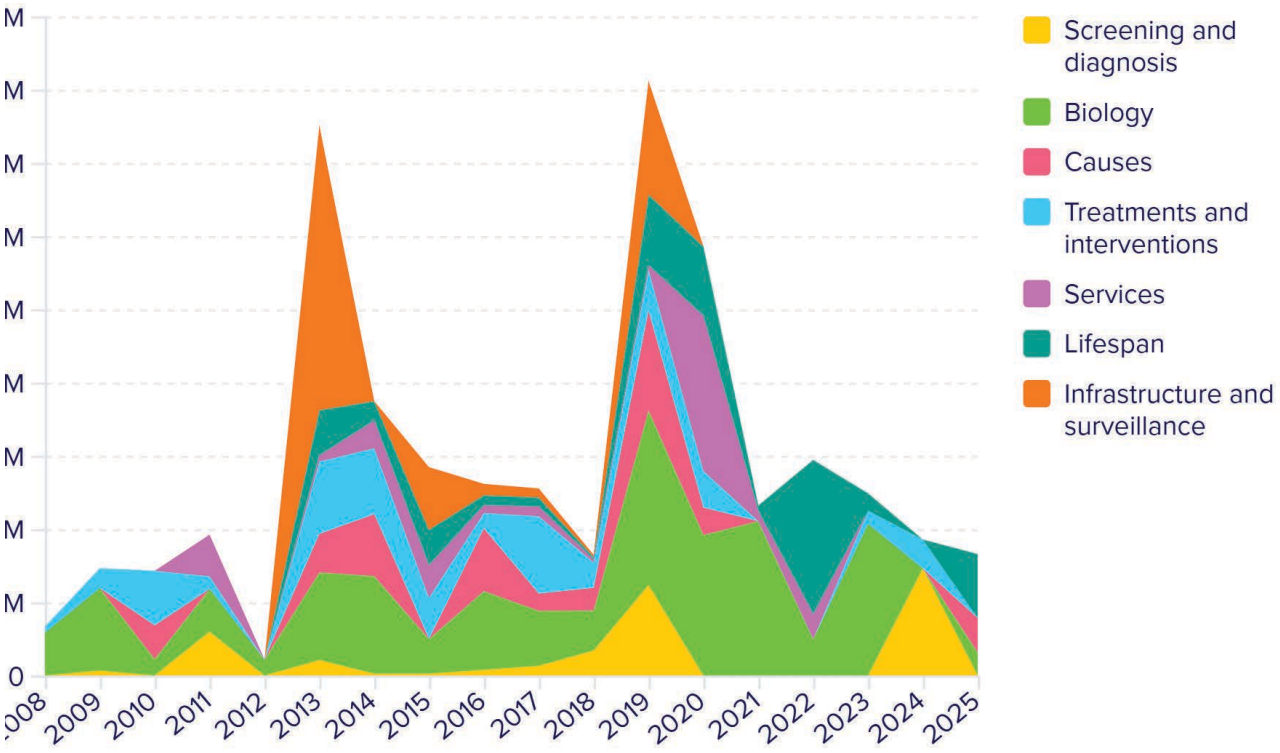
Figure 4.8: Australian autism research investment by year awarded, 2008–2025 (AUD)



Examining the relative distribution of funding across research topics provides some insight regarding factors that may underlie the year-to-year fluctuation in Australian autism research investment. As shown in Figure 4.9, the peak in funding awarded during 2013 is largely attributable to investment in research infrastructure and surveillance. Specifically, this peak reflects the 2013 establishment of Autism CRC and associated infrastructure and surveillance investments totalling more than AUD$7.5 million. The peak in funding awarded during 2019 reflects greater-than-usual investment across several research topics. This peak is associated with four substantial grants (with a collective value of just under AUD$8.5 million) awarded by the NHMRC for research across screening and diagnosis; biology; causes; and infrastructure and surveillance.

Figure 4.9 also reveals notable trends in the pattern of autism research investment across time. Prior to 2013, funding was largely concentrated in biological research, and research investigating treatments and interventions. 2013 saw funding awarded across all seven research topics for the first time. Research funding was granted across all seven topics each subsequent year until 2020 (with two exceptions: no funding was awarded for research infrastructure and surveillance during 2014, and no funding was awarded for research investigating causes of autism during 2015). From 2021 onwards, distribution of investment again narrowed, with funding awarded across no more than three research topics in any year. From 2021, the pattern of autism research investment across topics is comparable to the pre-2013 pattern, with the notable exception of increased investment in lifespan issues research across recent years.

Figure 4.9: Distribution of Australian autism research funding 2008–2025 (AUD)



4.4 Summary

Total investment in autism research during the study period amounted to approximately AUD$81.7 million in Australia and NZD$10.9 million in Aotearoa New Zealand. Notably, grant sizes varied substantially, with median funding levels in Aotearoa New Zealand approximately one-third lower than those observed in Australia, even after accounting for exchange rates. This discrepancy reflects broader differences in research funding landscapes across the two countries.

Funding distribution across research topics revealed a strong emphasis on basic scientific research in both countries. In Australia, biological research accounted for the largest share of funding (34%), receiving more than AUD$25 million, followed by lifespan issues (16%), with both infrastructure and surveillance, and treatment and intervention, each receiving roughly 13%, and causes, services, and screening and diagnosis each received around 9%. In contrast, Aotearoa New Zealand allocated 35% of funding to biological research, but demonstrated a relatively greater proportional investment in treatment and intervention (31%) and services (27%). Notably, no grants were identified that aligned with the categories of screening and diagnosis or lifespan issues in Aotearoa New Zealand during the study period.

Analysis of project counts broadly mirrored funding patterns, suggesting that observed disparities were not solely attributable to differences in individual project cost structures. Biological research attracted the highest number of grants in both countries. As discussed in the opening section of this chapter, substantial evidence has been amassed showing that community research priorities consistently favour applied research over basic science. In spite of this, researchers continue to pay a great deal of attention to these areas and are well supported by the funding bodies that finance this research.

An interesting feature of the data from Aotearoa New Zealand was the presence of three research projects that did not align with any of the IACC subcategories. Specifically, these grants focussed on culturally safe and neurodiversity affirming supports for First Nations communities; co-design of autism specific resources incorporating Indigenous knowledge; and the impact of positive framing of autism on the wellbeing of autistic children. This misalignment may indeed be representative of a shift towards research that eschews the conventional structures of the hard sciences to capture a greater diversity of stakeholder voices and embrace methods of knowledge production beyond the medical paradigm of Western science.

The particular emphasis on basic sciences in Australian autism research may be attributable to the dominance of the NHMRC on the research funding landscape. The NHMRC awarded over AUD$37 million across 38 autism research projects from 2018–2025, representing 46% of the total funding identified in this portfolio analysis. Of that funding awarded by the NHMRC, almost half (47%) went to biological research, with an additional 17% to research focussed on causes. This is reflective of a point of friction between the research foci prioritised by the biggest funder of autism research in Australia and the aspirations of the autistic community.

This portfolio analysis had the benefit of drawing from the dataset from den Houting and Pellicano's (2019) study to enable a longitudinal view of autism research funding patterns in Australia over a period of 18 years. While biology remained the dominant category represented in research funding throughout, there was an interesting shift in the funding patterns beginning in 2013. This was spurred on by the first round of research investment by the Autism CRC and was the first year in the dataset where funding was allocated to every category. Though the NHMRC was responsible for almost half of the Australian research funding in these analyses, the Autism CRC funded almost

half of the research projects, awarding 68 of the 138 autism research grants active in Australia from 2018–2025.

Cooperative Research Centres in Australia are established for a limited time period, with the Autism CRC finishing its term in mid-2022 (Autism CRC, 2021). Though it continues to operate beyond its initial term, it no longer awards research grants. After 2022, the funding landscape, for the most part, reverted to the patterns seen prior to 2013. However, lifespan issues, a category not represented in the data from 2008 to 2013, has been retained as a focus area. Over half of the research grants awarded in 2025 addressed lifespan issues, a research area that has been consistently highlighted as a community priority.

5. Alignment between autistic and autism community priorities, research activity and funding: Australia

The purpose of this section is to explore the extent to which autism research in Australia is aligned with the issues identified by autistic people, families, and stakeholders through formal consultation processes, the topics identified in research priority-setting studies and funding.

It is therefore necessary to examine overlap and divergence across four sections presented in this report:

1. community-identified issues raised in autism-focussed community consultations (section 1)
2. published research papers related to autism (section 2)
3. research priority-setting outputs related to autism (section 3), and
4. autism research grants funded between 2018–2025 (section 4).

Community consultation submissions reflect lived/living experience and system interaction outside of research settings. They capture the practical, day-to-day challenges, unmet needs, and priorities articulated in policy-facing forums. However, these issues are not automatically translated into research activity.

Research priority-setting studies attempt to bridge this gap by engaging stakeholders in structured processes to identify research questions of importance. While these exercises bring community voice into research planning, participation still requires engagement within a research framework and may not fully capture the breadth of issues raised in broader public consultations.

Published research provides a third lens. Unlike consultation submissions or priority-setting exercises, this reflects the areas in which research activity has been undertaken and successfully published. As such, it provides insight into where scholarly attention, methodological effort, and research investment have been directed in practice.

By examining autism research published in Australia between 2023 and 2025 alongside the other community issues and research priority-setting studies, we are able to assess the degree of alignment, or misalignment, between community-identified issues, articulated research priorities, and the research that is ultimately produced and funded. Considering these areas together allows for a clearer understanding of whether the issues experienced by autistic people, families, and stakeholders are reflected in contemporary research activity (including priority setting), and where gaps may remain.

1. **Community relevance of research:** the proportion of Australian research that directly addresses identified community issues and/or research priorities.
2. **Key empirical knowledge gaps,** where community-identified issues or research priorities are not currently addressed by Australian research activity. For those identified, we checked to see if this is a total empirical knowledge gap or a geographical gap. To do this, for each key Australian issue not being addressed in Australian research, a Google search was undertaken to identify if research papers are present in the international evidence base.

3. **Research-translation gaps,** where research evidence exists but communities continue to report persistent problems, suggesting limited policy or practice uptake.

Heatmaps to support strategic interpretation of the findings have been created. These visually represent alignment (and misalignment) between community-identified priorities/issues and current research activity. The heatmaps combine multiple indicators – community ranking, endorsement in research priority-setting exercises, and the volume of recent empirical research. Rather than examining each metric in isolation, the heatmaps provide a consolidated view of relative need and activity across the landscape. This supports clearer interpretation of where future research focus or investment, policy attention, or implementation effort may be most strategically directed.

Each heatmap contains two complementary columns:

1. **Research translation potential** (left-hand column): areas that have a substantial evidence base but are prioritised and frequently reported by the community; higher scores identify issues where evidence exists and community concern persists, indicating a high potential for translating existing research for community benefit.
2. **Research need** (right-hand column): issues that are highly reported and prioritised by the community but remain underexamined in recent empirical research. Higher scores highlight areas where community-prioritised concerns appear comparatively underexamined in recent empirical research, suggesting potential areas for strategic research development.

A description of how these scores were calculated is in Appendix A.

The analysis then integrates findings related to **research funding**. This provides an additional perspective by showing where investment is being directed and, consequently, which areas are most likely to shape the future research landscape. Autism research grants funded between 2018 and 2025 described in the Funding Portfolio Section were also aligned to the community issue framework. Grants were only aligned only if the funded activity clearly addressed a community-identified issue. Each grant could be coded to a maximum of two community issues. The amount and number of grants funded within the table below therefore provides an indication of the extent to which community-identified issues have been reflected in funded autism research activity. Because grants could be coded to more than one issue, a grant may appear in multiple rows. Consequently, grant counts and funding values should not be summed across issues to calculate overall totals.

Finally, at the end of this section, **population gaps** are also identified. This highlights demographic groups underrepresented in community consultations and research priority-setting processes. This alignment analysis moves discussion beyond volume of research and into considering relevance, responsiveness, and equity of the research conducted. It provides an evidence-informed foundation for shaping future research focus, funding allocation, and translation strategies aimed at reducing the systemic gaps identified by autistic people and their communities.

5.1 Alignment of community issues, research priorities, research outputs and funding by domain

5.1.1 Diagnosis

Table 5.1 shows the aspects of data explored in this report, relating to autistic people's experiences with autism diagnosis. First, it presents community-identified issues on the topic, as coded from public consultation submissions. Second, it reports the number of Australian research priority-setting studies that identified a priority aligned with each issue. Third, it presents the number of Australian research papers published between 2023 and 2025 (total n = 510) and the number and total AUD$ of grants awarded to researchers that addressed the issue, either by describing the problem or evaluating approaches to improve it.

By presenting these side-by-side, the table enables direct comparison between lived/living experience community issues, articulated research priorities, and contemporary research activity and investments within the domain of diagnosis.

Table 5.1: Alignment – Diagnosis

Rank	Community issue – Diagnosis	% of submissions coded to this issue (overall) Total *N* = 1,575	Australian research priority reports that prioritise this issue (Yes ✓ / No × number of reports identified in)	Australian research papers related to this issue (2023–2025) (Yes ✓ / No ×, number of papers on topic)	Australian funding addressing this issue (Yes ✓ / No ×, number and AUD$ value of grants on topic)
1	**Delays in assessment or diagnosis**	24.4	✓ 3	✓ 10	✓ 7 $4,944,034
2	**High costs associated with accessing assessment and diagnosis**	20.9	✓ 1	✓ 2	× 0
3	**A lack of autism awareness, understanding, and/or training for diagnosis, including knowledge of autism's heterogeneity and associated needs**	19.2	✓ 2	✓ 5	✓ 3 $1,382,406
4	**A lack of multidisciplinary and comprehensive approach to assessment and diagnosis**	6.2	× 0	✓ 2	✓ 1 $259,500
5	**Issues with the reliability of diagnostic and assessment methods and processes**	4.1	✓ 1	✓ 7	✓ 4 $1,074,206
6	**Gender-based inequities in access to or delivery of assessment and diagnosis**	3.3	✓ 3	✓ 6	× 0
7	**A lack of knowledge and specialised care for those with co-occurring conditions**	1.2	× 0	✓ 6	✓ 1 $2,500,000

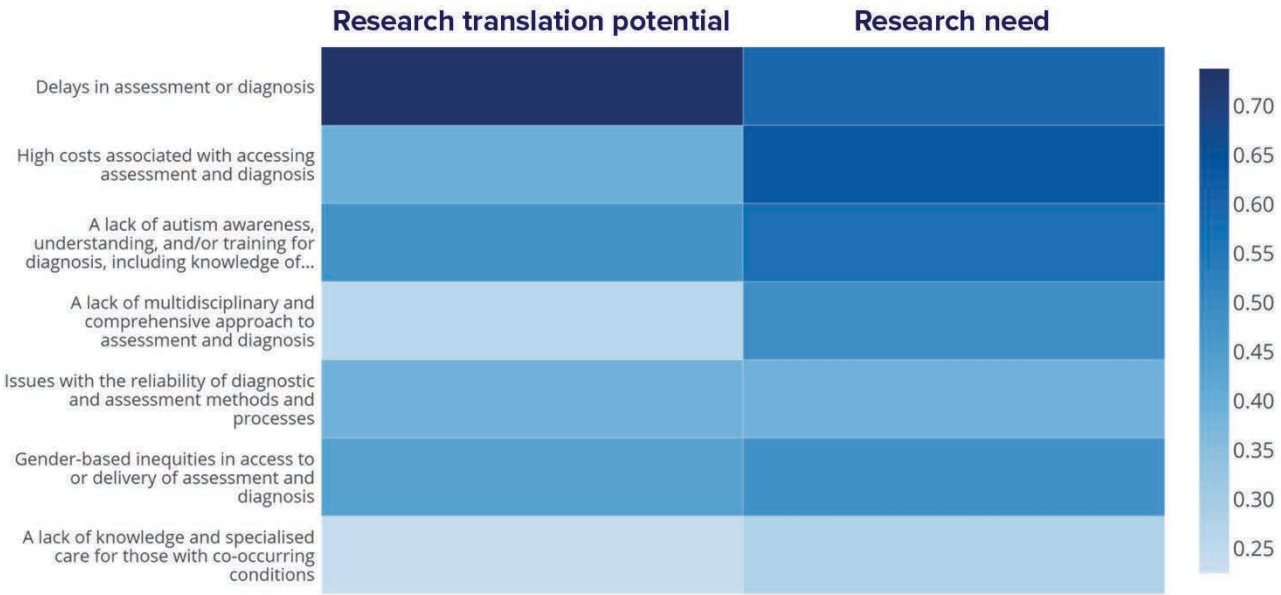
Community relevance of diagnosis research. Alignment across community consultations, research priority-setting outputs, and recent Australian research in the diagnosis domain was strong but uneven. Of the 510 Australian empirical papers published between 2023 and 2025 that were reviewed for this project, 36 were coded to diagnosis. Of those and 206 coded into the 'other' domain, 31 addressed Australian community-identified issues related to diagnosis. The most frequently coded community issue, delays in assessment and diagnosis, was prioritised in three research priority-setting studies and addressed in 10 recent empirical papers, indicating particularly strong alignment in this area.

Key empirical knowledge gaps. While every community-identified issue had at least some research coverage, high costs associated with assessment and diagnosis and lack of a comprehensive and multidisciplinary approach were each addressed in only two recent papers, indicating empirical knowledge gaps. A Google Scholar search showed that all of these areas are covered in at least one empirical paper from outside Australia; therefore, these are geographical gaps rather than total empirical knowledge gaps.

Research-translation gaps. Delays in assessment and diagnosis and lack of autism awareness and training for diagnosis were both addressed in multiple recent studies yet remain prominent in consultation submissions, indicating opportunities for research translation.

The heatmap in Figure 5.1 shows that "Delays in assessment or diagnosis" has the highest immediate research translation potential score and "High costs associated with accessing assessment and diagnosis" has the highest research need score (although noting Delays in assessment or diagnosis and A lack of autism awareness, understanding, and/or training for diagnosis, including knowledge of autism's heterogeneity and associated needs, had similar but lower ranking scores).

Figure 5.1: Heatmap indicating empirical knowledge gaps and research translation opportunities for the domain of diagnosis.



Funding Alignment: Funding in the area of diagnosis aligns with several community-identified issues, although not all highly ranked issues received funding. The largest amount and highest number of grants were coded to the most frequently identified community issue (delays in assessment or diagnosis, raised in 24.4% of community submissions). Seven grants worth $4.94 million aligned with this community issue. Multiple grants were also coded to two other community issues: a lack of autism awareness and training for diagnosis (third most frequently reported community issue) and issues with reliability of diagnostic and assessment methods (fifth most frequently reported community issue). However, no grants were coded to the second most commonly identified community issue (high costs of assessment and diagnosis), despite it being reported in 20.9% of submissions to public consultations or surveys.

5.1.2 Early intervention and supports

Using the same alignment framework described above, Table 5.2 presents community-identified issues, research priorities, published research and funding awarded relating to early intervention and supports.

Table 5.2: Alignment – Early intervention and supports

Rank	Community issue – Early intervention and supports	% of submissions coded to this issue (overall) Total *N* = 1,575	Australian research priority reports that prioritise this issue (Yes ✓ / No × number of reports identified in)	Australian research papers related to this issue (2023–2025) (Yes ✓ / No ×, number of papers on topic)	Australian funding addressing this issue (Yes ✓ / No ×, number and AUD$ value of grants on topic)
1	Inadequacy of early intervention services	17.4	× 0	✓ 11	✓ 9 $7,098,193
2	Delays in accessing early intervention services	12.7	× 0	✓ 2	✓ 1 $473,475
3	Limited access to early intervention services	12.2	× 0	✓ 3	✓ 1 $304,596

Note: Grants could be coded to a maximum of two community issues. As a result, a single grant may appear in more than one row. Grant counts and funding values represent the number and value of grants addressing each issue and should not be summed across rows to calculate overall totals.

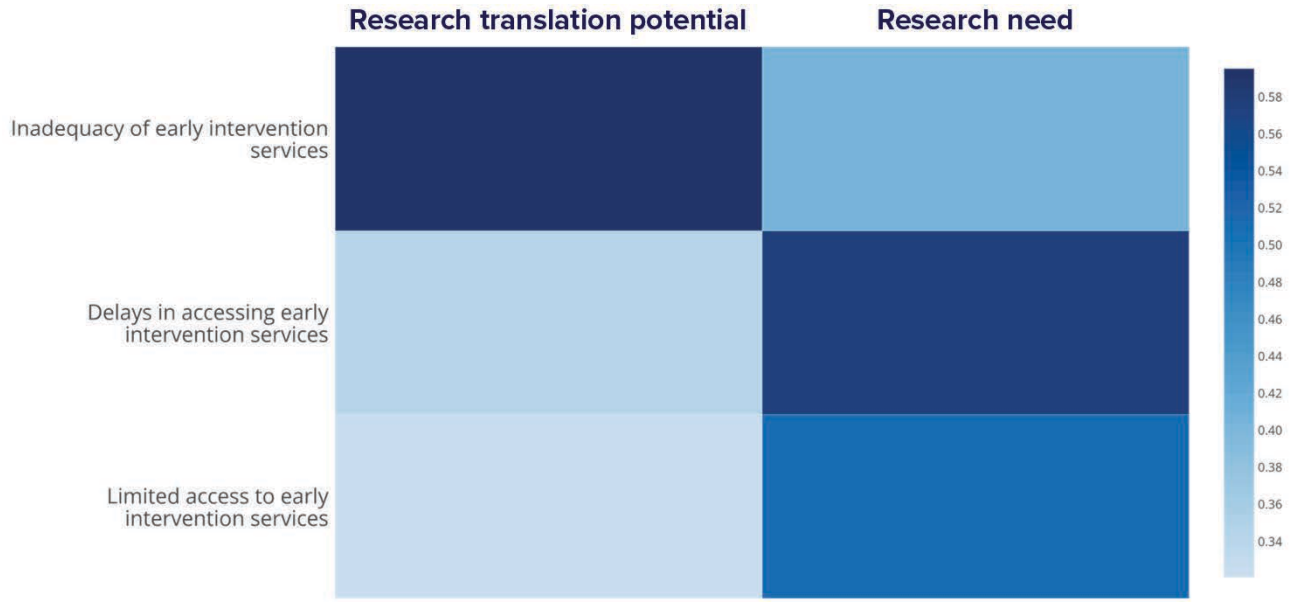
Community relevance of early intervention and supports research. Alignment across community consultations, research priority-setting outputs, and recent Australian research in the domain of early intervention and supports was partial. Of the 510 Australian empirical papers published between 2023 and 2025 that were reviewed for this project, 92 were coded to early intervention or supports. From those and the 206 papers coded into the ‘other’ category, 13 addressed the specific community-identified issues in this category. The small proportion of alignment is in part due to community submissions focusing on the early years and the broader research exploring supports across all ages.

Key empirical knowledge gaps. Delays in accessing early intervention and limited access to early intervention services were addressed in only two to three papers each, indicating limited empirical coverage of these highly ranked concerns.

Research-translation gaps. Inadequacy of early intervention services was addressed in 11 recent studies yet remains the most frequently raised community issue, suggesting opportunities for stronger research translation.

The heatmap in Figure 5.2 shows that "Inadequacy of early intervention services" has the highest immediate research translation potential score and "Delays in accessing early intervention services" has the highest research need score.

Figure 5.2: Heatmap indicating empirical knowledge gaps and research translation opportunities for the domain of early intervention and supports



Funding alignment: grants were coded to all three community-identified issues in the area of early intervention, with the largest amount and highest number of grants aligned to the most frequently identified issue, inadequacy of early intervention services (raised in 17.4% of community submissions). Nine grants worth $7.1 million were coded to this issue. One grant was coded to delays in accessing early intervention services and one grant was coded to limited access to early intervention services, the second and third most frequently identified issues, respectively.

5.1.3 Education

Using the same alignment framework described above, Table 5.3 presents community-identified issues, research priorities, published research and funding awarded relating to education.

Table 5.3: Alignment – Education

Rank	Community issue – Education	% of submissions coded to this issue (overall) Total *N* = 1,575	Australian research priority reports that prioritise this issue (Yes ✓ / No × number of reports identified in)	Australian research papers related to this issue (2023–2025) (Yes ✓ / No ×, number of papers on topic)	Australian funding addressing this issue (Yes ✓ / No ×, number and AUD$ value of grants on topic)
1	**A lack of autism awareness, understanding, and/or training among educators, including knowledge of autism's heterogeneity and the diverse needs of autistic students**	36.7	✓ 5	✓ 8	✓ 8 $1,267,229
2	**Limited consideration of environmental support requirements**	36.3	✓ 4	✓ 5	✓ 1 $273,000
3	**Limited or inconsistent delivery of education tailored to individual needs and preferences**	31.2	✓ 5	✓ 14	✓ 12 $3,669,400
4	**Educational exclusion or lack of inclusion**	20.3	✓ 3	✓ 3	✓ 8 $2,549,501
5	**Limited access to educational support**	12.0	✓ 3	✓ 5	✓ 3 $1,583,138
6	**Lack of public or community education on autism**	4.0	✓ 4	✓ 5	× 0
7	**Limited collaboration between educators and families to inform decision-making**	2.2	✓ 2	✓ 11	✓ 3 $377,900
8	**Gender-based inequities in access to or delivery of education**	0.3	✓ 3	× 0	× 0

Note: Grants could be coded to a maximum of two community issues. As a result, a single grant may appear in more than one row. Grant counts and funding values represent the number and value of grants addressing each issue and should not be summed across rows to calculate overall totals.

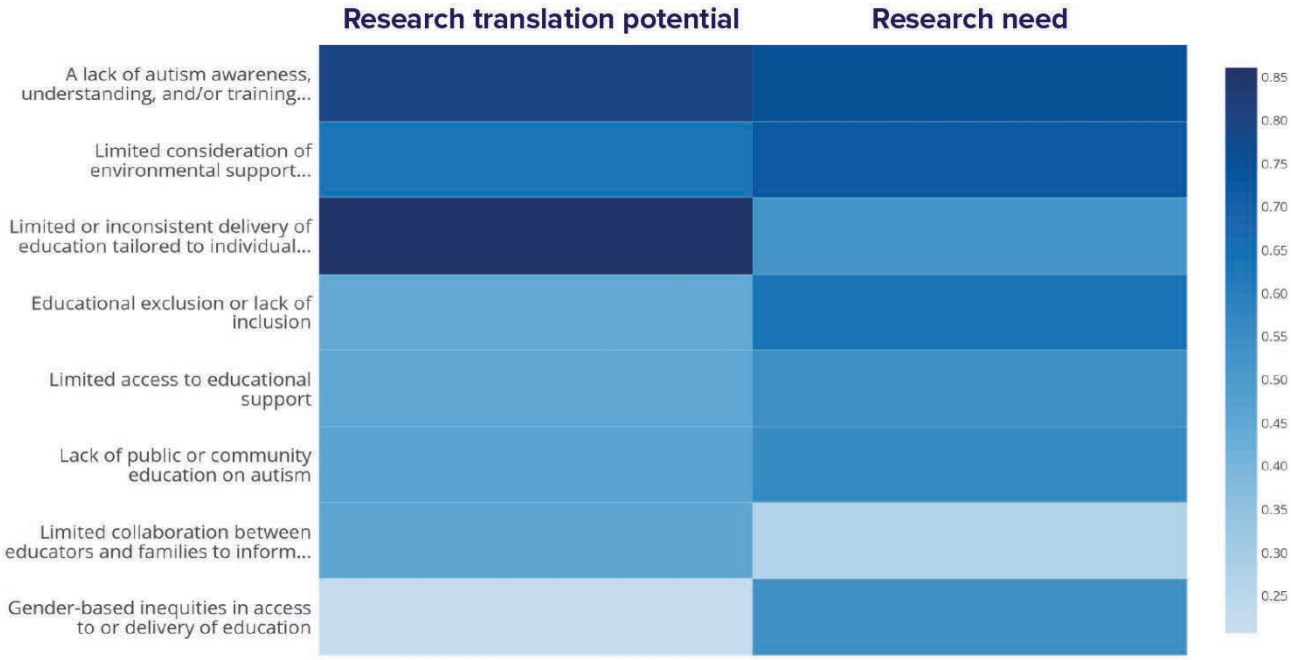
Community relevance of education research. Alignment across community consultations, research priority-setting outputs, and recent Australian research in the education domain was strong. Of the 510 Australian empirical papers published between 2023 and 2025 that were reviewed for this project, 51 were coded to education. Of that 51 and the 206 coded as 'other', 38 addressed Australian community-identified issues related to education. Seven of the eight community-identified education issues were addressed in three or more recent research outputs. The three highest ranked concerns were prioritised in the majority of the research priority-setting exercises and described or addressed in a total of 27 empirical studies.

Key empirical knowledge gaps. Gender-based inequities in access to or delivery of education were identified in three research priority-setting outputs but were not addressed in any recent Australian research, indicating a key empirical knowledge gap.

Research-translation gaps. Highly ranked issues such as educator awareness and training, environmental supports, and tailored educational delivery were addressed in multiple studies yet remain prominent in consultation submissions, indicating opportunities for more impactful research translation.

The heatmap in Figure 5.3 shows that "Limited or inconsistent delivery of education tailored to individual needs and preferences" has the highest immediate research translation potential score and "A lack of autism awareness, understanding, and/or training among educators, including knowledge of autism's heterogeneity and the diverse needs of autistic students" has the highest research need score (noting that "Limited consideration of environmental support requirements" has a similar score but ranked second).

Figure 5.3: Heatmap indicating empirical knowledge gaps and research translation opportunities for the domain of education



Funding alignment: funding aligned with some, but not all, of the community-identified issues in the area of education. The largest amount and highest number of grants were coded to the third most frequently identified issue, limited or inconsistent delivery of education tailored to individual

needs and preferences (identified in 31.2% of community submissions). Twelve grants worth $3.67 million were coded to this issue. Multiple grants were also coded to the most frequently identified issue, a lack of autism awareness, understanding, and/or training among educators (identified in 36.7% of community submissions), and the fourth most frequently identified issue, educational exclusion/lack of inclusion (identified in 20.3% of community submissions). However, only one grant worth $273,000 was coded to the second most frequently identified issue, limited consideration of environmental support requirements, despite it being identified in 36.3% of community submissions. No grants were coded to two other community-identified issues: lack of public or community education on autism and gender-based inequities in access to or delivery of education.

5.1.4 Employment

Using the same alignment framework described above, Table 5.4 presents community-identified issues, research priorities, published research and funding awarded relating to education.

Table 5.4: Alignment – Employment

Rank	Community issue – Employment	% of submissions coded to this issue (overall) Total *N* = 1,575	Australian research priority reports that prioritise this issue (Yes ✓ / No × number of reports identified in)	Australian research papers related to this issue (2023–2025) (Yes ✓ / No ×, number of papers on topic)	Australian funding addressing this issue (Yes ✓ / No ×, number and AUD$ value of grants on topic)
1	**Workplace exclusion**	40.1	✓ 2	✓ 7	✓ 1 $451,583
2	**Barriers to obtaining and sustaining employment**	29.0	✓ 3	✓ 10	✓ 6 $1,708,077
3	**A lack of autism awareness and/ or training among employers and employees**	16.8	✓ 2	✓ 4	✓ 2 $476,028
4	**A lack of autistic-specific employment initiatives**	7.5	✓ 3	✓ 5	✓ 7 $1,286,158

Note: Grants could be coded to a maximum of two community issues. As a result, a single grant may appear in more than one row. Grant counts and funding values represent the number and value of grants addressing each issue and should not be summed across rows to calculate overall totals.

Community relevance of employment research. Alignment across community consultations, research priority-setting outputs, and recent Australian research in the employment domain was strong. Of the 510 Australian empirical papers published between 2023 and 2025 reviewed, 16 were coded to employment. Of that 16 and the 206 coded as 'other', 14 addressed Australian community-identified issues. All four community-identified employment issues were reflected in research priority-setting papers and addressed in recent empirical research.

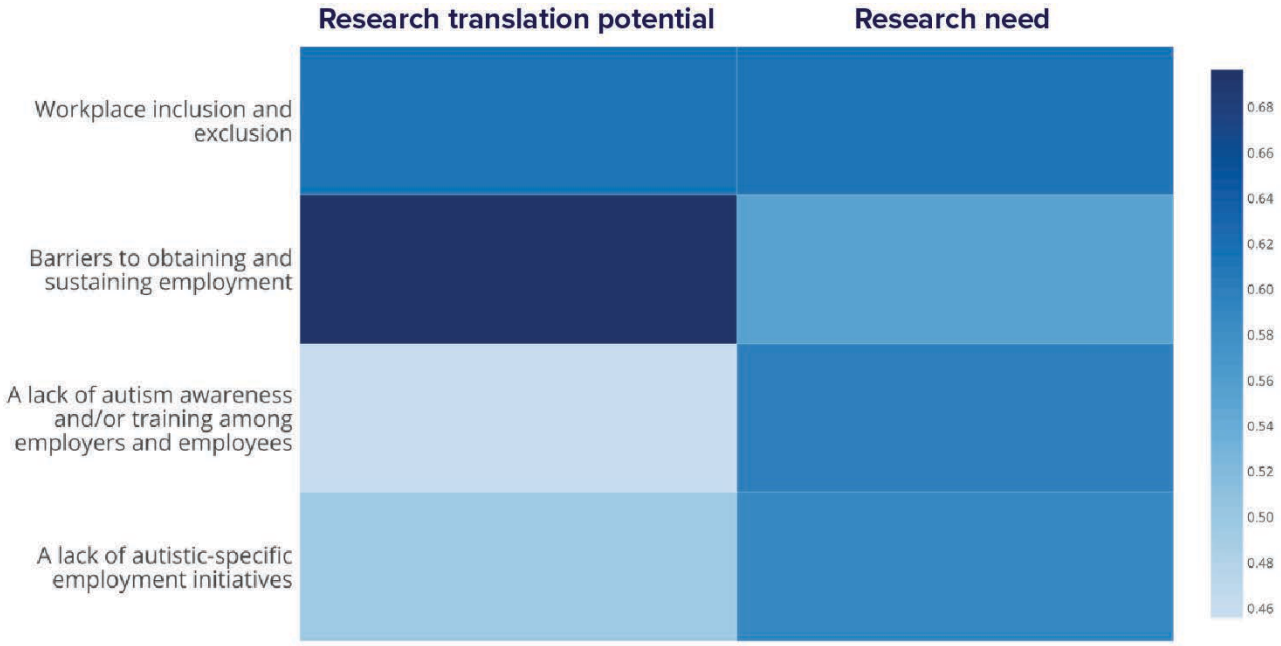
Key empirical knowledge gaps. While each community-identified employment issue was addressed in recent research, the total number of papers which were coded to employment was small (16), indicating opportunities for growth in this research category.

Research-translation gaps. All four community-identified employment issues were reflected in

priority-setting papers and addressed in current research, indicating high relevance and clear opportunities for research translation.

The heatmap in Figure 5.4 shows that “Barriers to obtaining and sustaining employment” has the highest immediate research translation potential score and “Workplace exclusion” has the highest research need score (although noting that both “A lack of autism awareness and/or training among employers and employees” and “A lack of autistic-specific employment initiatives” have very similar research need scores to the area of workplace exclusion).

Figure 5.4: Heatmap indicating empirical knowledge gaps and research translation opportunities for the domain of employment



Funding alignment. Funding was identified across all four employment-related community issues, suggesting some breadth of investment in this domain. However, the distribution of funding did not closely follow the frequency with which issues were raised in community consultations. The largest investment was directed to barriers to obtaining and sustaining employment, the second most frequently identified issue, with six grants worth $1.7 million. The highest number of grants was coded to autistic-specific employment initiatives, despite this being the least frequently identified employment issue, with seven grants worth $1.29 million. In contrast, workplace exclusion was the most frequently raised employment issue, identified in 40.1% of submissions, but attracted only one grant worth $451,583. This suggests that while employment funding is present, it is more strongly oriented towards employment pathways and initiatives than towards the broader workplace cultures and exclusionary practices most often identified by the community.

5.1.5 Housing and independent living

Using the same alignment framework described above, Table 5.5 presents community-identified issues, research priorities, published research and funding awarded relating to housing and independent living.

Table 5.5: Alignment – Housing and independent living

Rank	Community issue – Housing and independent living	% of submissions coded to this issue (overall) Total *N* = 1,575	Australian research priority reports that prioritise this issue (Yes ✓ / No × number of reports identified in)	Australian research papers related to this issue (2023–2025) (Yes ✓ / No ×, number of papers on topic)	Australian funding addressing this issue (Yes ✓ / No ×, number and AUD$ value of grants on topic)
1	**A lack of suitable supported accommodation**	22.3	✓ 4	× 0	× 0
2	**Limited access to resources and support for developing independent living skills**	4.8	✓ 3	✓ 13	✓ 4 $998,322
3	**A lack of accessible public facilities to support independent living**	2.2	✓ 3	✓ 9	✓ 1 $323,546

Note: Grants could be coded to a maximum of two community issues. As a result, a single grant may appear in more than one row. Grant counts and funding values represent the number and value of grants addressing each issue and should not be summed across rows to calculate overall totals.

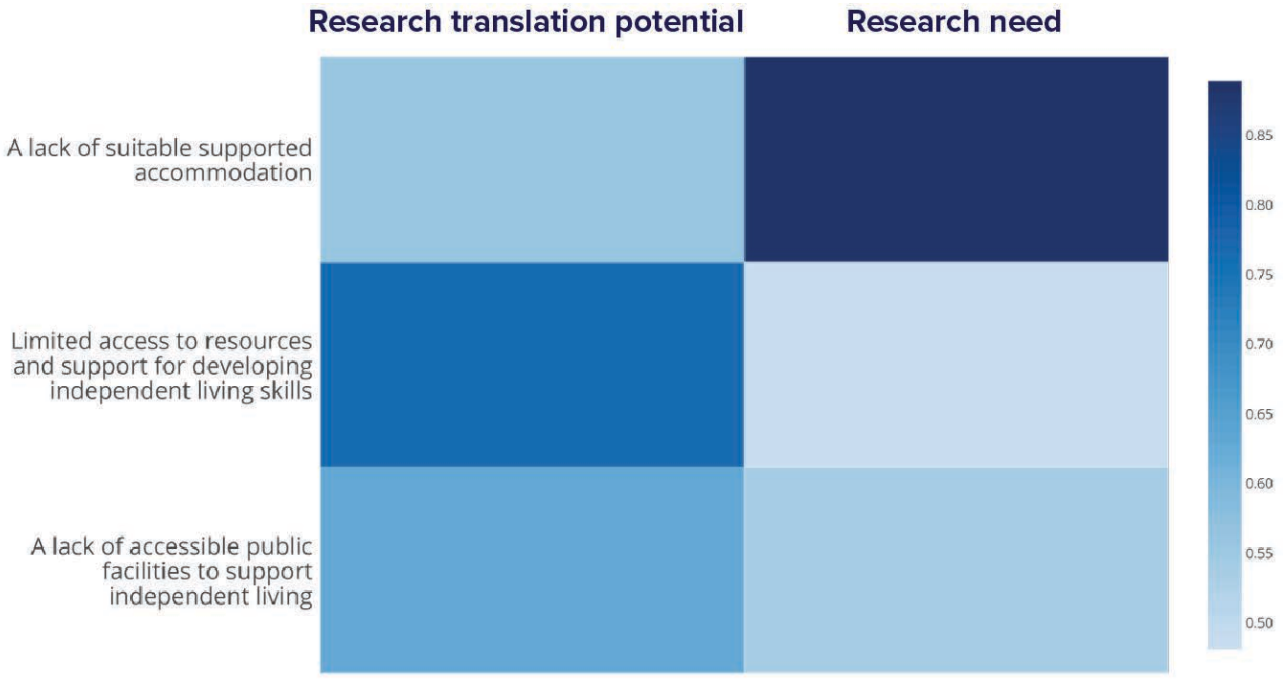
Community relevance of housing and independent living research. Alignment across community consultations, research priority-setting outputs, and recent Australian research in the housing and independent living domain was mixed. Of the 510 Australian empirical papers published between 2023 and 2025 reviewed, 16 were directly coded to the employment domain and an additional four were coded under the 'other' domain. Of the 16 and the 206 papers coded as other, 20 empirical papers addressed community-identified issues. All three community-identified issues were reflected in research priority-setting outputs.

Key empirical knowledge gaps. The highest ranked issue, a lack of suitable supported accommodation, was identified in multiple research priority-setting papers but was not addressed in any recent Australian research, indicating a significant empirical knowledge gap.

Research-translation gaps. Limited access to independent living skills supports and lack of accessible public facilities were addressed in recent research and reflected in research priority-setting outputs, indicating opportunities for research translation.

The heatmap in Figure 5.5 shows that “Limited access to resources and support for developing independent living skills” has the highest immediate research translation potential score and “Limited access to resources and support for developing independent living skills” has the highest research need score.

Figure 5.5: Heatmap indicating empirical knowledge gaps and research translation opportunities for the domain of housing and independent living



Funding alignment. Funding for housing and independent living was limited and did not align with the issue most frequently raised by the community. Investment was directed towards independent living skills, with four grants worth $998,332, and accessible public facilities, with one grant worth $329,456. However, no grants were coded to the most frequently identified issue in this domain, a lack of suitable supported accommodation, despite this being raised in 22.3% of community submissions. This indicates a clear funding gap in relation to housing options themselves, with existing investment focused more on supporting independence within current environments than on addressing the availability, suitability, or accessibility of accommodation.

5.1.6 Justice system

Using the same alignment framework described above, Table 5.6 presents community-identified issues, research priorities, published research and funding awarded relating to experiences with the justice system.

Table 5.6: Alignment – Justice system

Rank	Community issue – Justice system	% of submissions coded to this issue (overall) Total *N* = 1,575	Australian research priority reports that prioritise this issue (Yes ✓ / No × number of reports identified in)	Australian research papers related to this issue (2023–2025) (Yes ✓ / No ×, number of papers on topic)	Australian funding addressing this issue (Yes ✓ / No ×, number and AUD$ value of grants on topic)
1	**A lack of autism awareness, understanding, and/or training among criminal justice professionals** (e.g., law enforcement, prison staff)**, including knowledge of autism's heterogeneity and associated needs**	12.6	✓ 2	✓ 4	✓ 1 $437,358
2	**Heightened vulnerability in the criminal justice system due to systemic gaps**	4.8	✓ 1	✓ 2	✓ 1 $437,358
3	**A lack of support, rehabilitation, and reintegration options**	4.2	✓ 1	× 0	× 0
4	**Over-representation of autistic people in the criminal justice system**	0.7	✓ 1	× 0	× 0

Note: Grants could be coded to a maximum of two community issues. As a result, a single grant may appear in more than one row. Grant counts and funding values represent the number and value of grants addressing each issue and should not be summed across rows to calculate overall totals.

Community relevance of justice research. Overall, alignment between community-identified issues and recent research in this category was limited. Out of the 510 Australian empirical articles published between 2023 and 2025, 11 were coded to the justice system category, making it the smallest research category in this review. Across these 11 and the 206 articles coded as 'other', five addressed Australian community-identified justice issues. The highest ranked issue (a lack of autism awareness, understanding, and training among criminal justice professionals) was addressed in four studies.

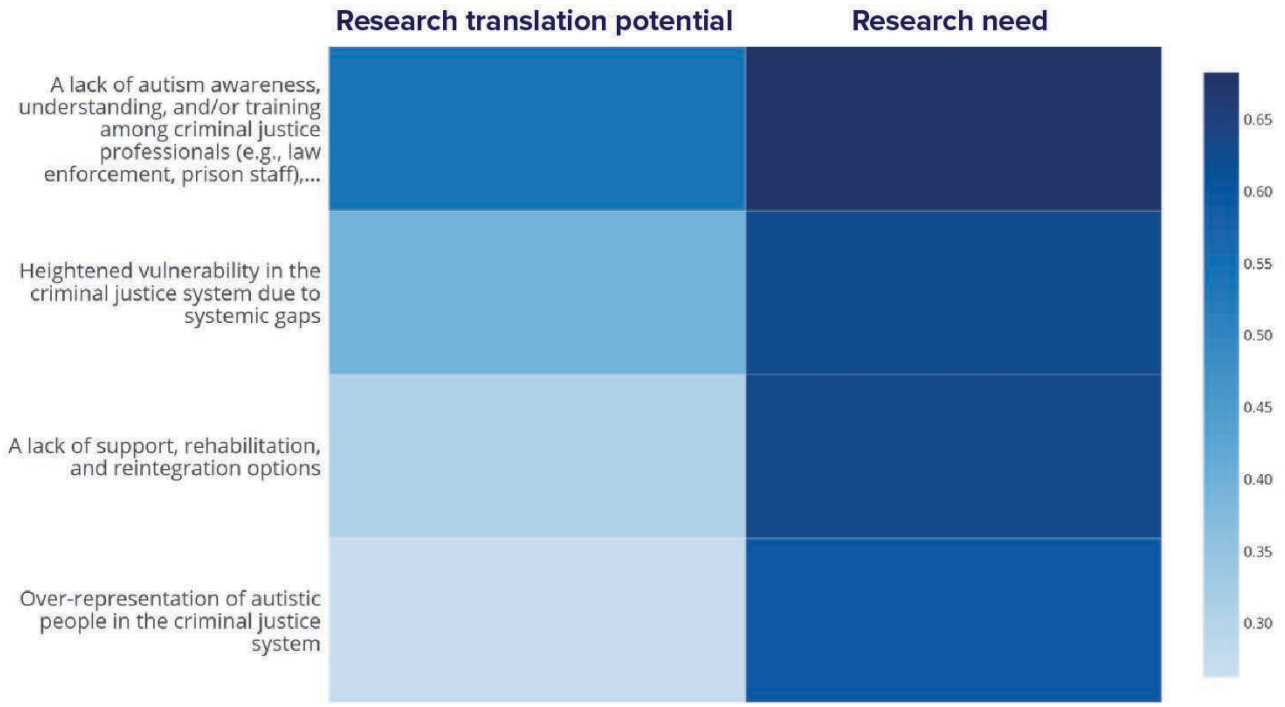
Key empirical knowledge gaps. Although the highest ranked issue was addressed in four studies, this level of coverage is limited relative to its prominence in consultation submissions. The third and fourth ranked community issues—lack of support, rehabilitation, and reintegration options, and over-

representation of autistic people in the criminal justice system—were not addressed in any recent Australian research. In addition, the small overall number of justice-system-focused studies indicates a broader empirical knowledge gap in relation to autistic people's interactions with the criminal justice system.

Research-translation gaps. The small number of studies examining professional awareness and heightened vulnerability in the system present emerging opportunities for research translation within this category.

The heatmap in Figure 5.6 shows that "A lack of autism awareness, understanding, and/or training among criminal justice professionals (e.g., law enforcement, prison staff), including knowledge of autism's heterogeneity and associated needs" has the highest immediate research translation potential score. All four areas had similarly high research needs score highlighting the significant need for research in this area.

Figure 5.6: Heatmap indicating empirical knowledge gaps and research translation opportunities for the domain of the justice system



Funding alignment. A single grant aligned with the two most frequently identified community issues in the area of the justice system. This grant, worth $437,358, was coded to both the most frequently identified issue (identified in 12.6% of community submissions) and the second most frequently identified issue (identified in 4.8% of community submissions). No grants were coded to the third or fourth ranked community issues, which related to support, rehabilitation, and reintegration and over-representation in the criminal justice system, respectively.

5.1.7 Physical health services

Using the same alignment framework described above, Table 5.7 presents community-identified issues, research priorities, published research and funding awarded relating to experiences with physical health services.

Table 5.7: Alignment – Physical health

Rank	Community issue – Physical health services	% of submissions coded to this issue (overall) Total *N* = 1,575	Australian research priority reports that prioritise this issue (Yes ✓ / No × number of reports identified in)	Australian research papers related to this issue (2023–2025) (Yes ✓ / No ×, number of papers on topic)	Australian funding addressing this issue (Yes ✓ / No ×, number and AUD$ value of grants on topic)
1	**A lack of autism awareness, understanding, and/or training among physical health professionals, including knowledge of autism's heterogeneity and associated needs**	33.3	✓ 4	✓ 5	✓ 2 $3,488,988
2	**Limited consideration of environmental support requirements**	23.7	✓ 4	✓ 3	× 0
3	**Limited availability of services and barriers to access**	15.5	✓ 4	✓ 6	✓ 1 $50,000
4	**High costs associated with accessing physical health services**	10.2	✓ 2	✓ 1	× 0
5	**Limited or inconsistent delivery of services that are tailored to individual needs and preferences**	10.1	✓ 4	✓ 4	✓ 5 $3,879,784
6	**Limited opportunities for autistic people or families to find out information or engage in informed decision-making**	4.3	✓ 2	✓ 3	× 0
7	**Gender-based inequities in access to or delivery of services**	0.5	✓ 3	✓ 2	× 0

Note: Grants could be coded to a maximum of two community issues. As a result, a single grant may appear in more than one row. Grant counts and funding values represent the number and value of grants addressing each issue and should not be summed across rows to calculate overall totals.

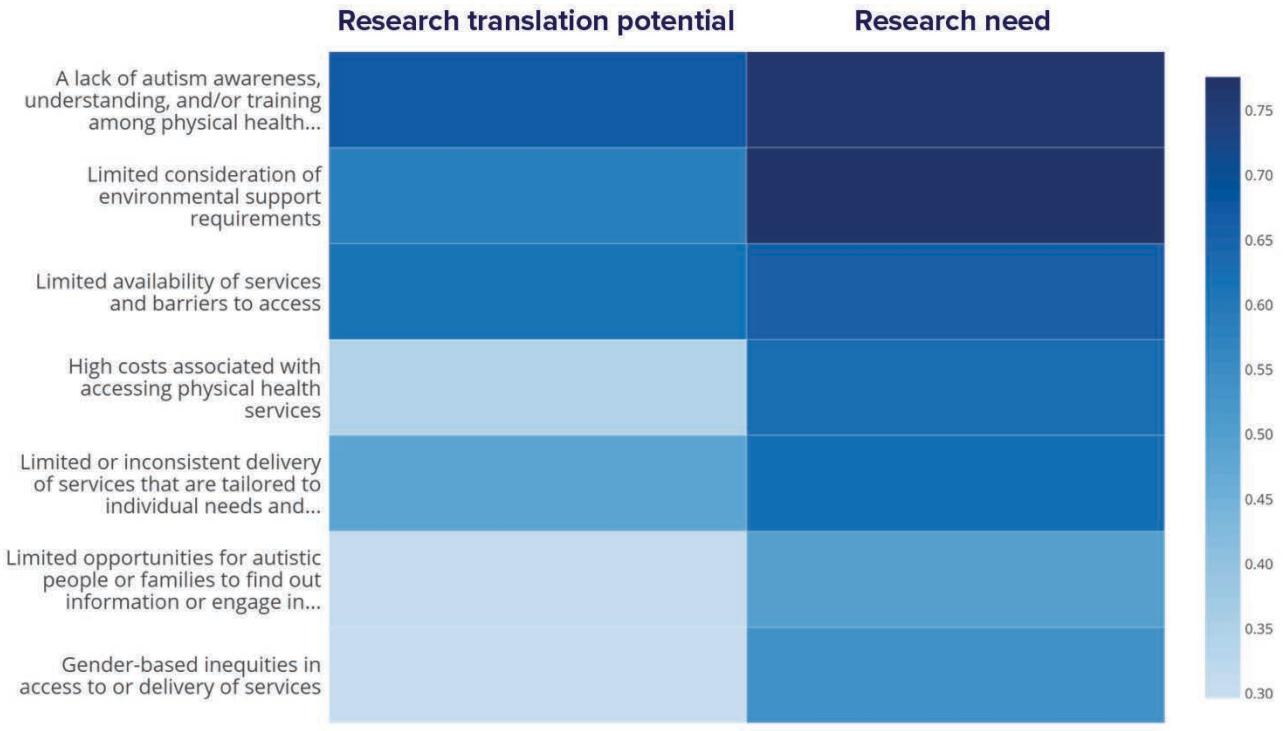
Community relevance of physical health research. Alignment across community consultations, research priority-setting outputs, and recent Australian research in the physical health domain was strong. Of the 510 Australian empirical papers published between 2023 and 2025 reviewed, 44 were coded to physical health. Across those and the 206 papers coded as other, 19 addressed Australian community-identified issues. All seven community-identified issues were addressed in at least one recent study.

Key empirical knowledge gaps. High costs associated with accessing physical health services (ranked fourth in consultation submissions) was addressed in only one recent Australian study, indicating a clear empirical knowledge gap in this area. Gender-based inequities in access to or delivery of physical health services (ranked seventh) were addressed in two studies. Although this issue was lower ranked within this domain, gender-based inequities were identified as priorities across several domains, suggesting a broader cross-domain empirical knowledge gap.

Research-translation gaps. Professional awareness and training, service availability and access barriers, and delivery of tailored care were examined in multiple recent studies yet remain prominent in consultation submissions, indicating opportunities for research translation.

The heatmap in Figure 5.7 shows that "A lack of autism awareness, understanding, and/or training among physical health professionals, including knowledge of autism's heterogeneity and associated needs" has the highest immediate research translation potential score. This also had the highest research need score, although "Limited consideration of environmental support requirements" had a similarly high research need score.

Figure 5.7: Heatmap indicating empirical knowledge gaps and research translation opportunities for the domain of physical health



Funding alignment. Funding in the area of physical health was coded to three of the seven community-identified issues. The fifth most frequently identified issue, individualised service delivery (identified in 10.1% of community submissions), received the largest amount of funding and highest number of grants, with five grants worth $3.88 million. Two grants worth $3.49 million were coded to the most frequently identified issue, autism awareness and training among physical health professionals (identified in 33.3% of community submissions). One grant worth $50,000 was coded to the third most frequently identified issue, service availability and access barriers (identified in 15.5% of community submissions). No grants were coded to the second, fourth, sixth, or seventh ranked community-identified issues, which related to environmental supports, service costs, access to information and informed decision-making, and gender-based inequities in service access and delivery, respectively.

5.1.8 Mental health services

Using the same alignment framework described above, Table 5.8 presents community-identified issues, research priorities, published research and funding awarded relating to experiences with mental health services.

Table 5.8: Alignment – Mental health

Rank	Community issue – Mental health services	% of submissions coded to this issue (overall) Total *N* = 1,575	Australian research priority reports that prioritise this issue (Yes ✓ / No × number of reports identified in)	Australian research papers related to this issue (2023–2025) (Yes ✓ / No ×, number of papers on topic)	Australian funding addressing this issue (Yes ✓ / No ×, number and AUD$ value of grants on topic)
1	A lack of autism awareness, understanding, and/or training among mental health professionals, including knowledge of autism's heterogeneity and associated needs	37.7	✓ 6	✓ 7	✓ 1 $37,880
2	Limited availability of services and barriers to access	21.0	✓ 3	✓ 1	× 0
3	High costs associated with accessing mental health services	10.6	× 0	× 0	× 0
4	Interventions are inappropriate or harmful	9.9	✓ 2	✓ 2	✓ 1 $557,029
5	Limited or inconsistent delivery of services that are tailored to individual needs and preferences	4.9	✓ 3	✓ 7	✓ 3 $4,988,369
6	Limited access to recreational facilities and social support groups	2.3	× 0	✓ 4	× 0
7	Limited opportunities for autistic people or their families to engage in informed decision-making	2.2	✓ 1	× 0	× 0
8	Limited consideration of environmental support requirements	0.9	✓ 2	× 0	× 0
9	Gender-based inequities in access to or delivery of services	0.8	✓ 1	✓ 1	✓ 1 $526,941

Note: Grants could be coded to a maximum of two community issues. As a result, a single grant may appear in more than one row. Grant counts and funding values represent the number and value of grants addressing each issue and should not be summed across rows to calculate overall totals.

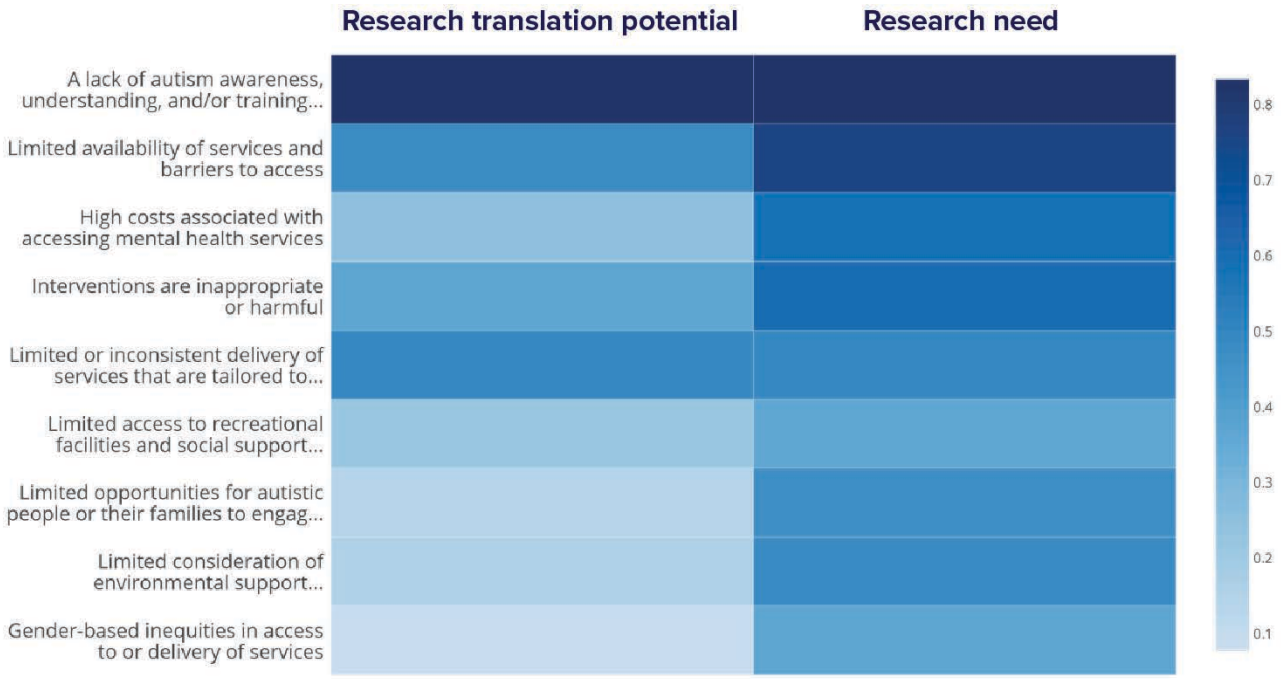
Community relevance of mental health research. Alignment across community consultations, research priority-setting outputs, and recent Australian research in the mental health domain was mixed. Of the 510 Australian empirical papers published between 2023 and 2025 reviewed, 80 were coded to mental health. Across those and the 206 coded to other, 17 addressed Australian community-identified issues. This represents a substantial discrepancy between the focus of research and the community-identified issues. The highest ranked issue—lack of autism awareness, understanding, and training among mental health professionals—was prioritised in all research priority-setting papers and addressed in seven empirical studies.

Key empirical knowledge gaps. Limited service availability and barriers to access, high costs, limited informed decision-making opportunities, environmental support needs, and gender-based inequities were minimally or not addressed in recent research.

Research-translation gaps. Despite research attention and priority-setting alignment, lack of autism awareness and training among mental health professionals remains prominent in consultation submissions, indicating opportunities for research translation.

The heatmap in Figure 5.8 shows that "A lack of autism awareness, understanding, and/or training among mental health professionals, including knowledge of autism's heterogeneity and associated needs" has both the highest immediate research translation potential score and the highest research need score.

Figure 5.8: Heatmap indicating empirical knowledge gaps and research translation opportunities for the domain of mental health



Funding alignment. Similar to physical health, funding in the area of mental health was concentrated on a small number of community-identified issues. The fifth most frequently identified issue, individualised service delivery (identified in 4.9% of community submissions), received the largest amount of funding and highest number of grants, with three grants worth $4.99 million. The fourth and ninth ranked issues each received a single grant worth approximately $0.5 million.

One grant worth $37,880 was coded to the most frequently identified issue, autism awareness and training among mental health professionals, which was identified in 37.7% of community submissions. No grants were coded to the five remaining community-identified issues relating to service availability and access barriers, service costs, access to recreational facilities and social support groups, informed decision-making, and environmental support requirements.

5.2 Cross-area gaps

5.2.1 Empirical knowledge gaps

Across domains, several empirical knowledge gaps were identified. While some gaps were specific to individual areas, others appeared consistently across multiple domains, pointing to broader structural blind spots within the current research landscape. These broader domain gaps are identified below as priorities for research investment.

A lack of autism awareness, understanding, and training among professionals was consistently raised across diagnosis, education, physical health services, mental health services, and the justice system. This issue is well described in multiple recent studies, however there is limited work demonstrating an effective way to improve knowledge and attitudes and none that crosses domains (e.g. education and health). **This highlights the need to fund research that moves beyond description to that which creates change and improves autism awareness and strengthens inclusive practice across education, healthcare, justice, and employment.**

Access and system-level barriers have also been inconsistently examined. In early intervention and supports, delays and limited access were addressed in only a small number of studies, with little empirical attention to eligibility processes, structural constraints, or service system design. Similar patterns were evident in mental health services and the justice system, where limited service availability, access barriers, rehabilitation, and reintegration supports received minimal attention. Combined, these findings suggest that while individual-level outcomes are frequently studied, but structural and systems-level determinants of access remain underdeveloped areas of inquiry.

One particular barrier that has received limited research attention is cost; high costs associated with diagnosis and physical health services were addressed in only a small number of studies, and high costs related to mental health services were not addressed at all. Despite being consistently raised in community consultations, financial barriers remain minimally explored in the recent Australian evidence base. **Addressing barriers (including the cost) of accessing supports should therefore be a priority for future research investment.** This includes developing and evaluating a broader range of accessible, lower-cost support options that reduce barriers such as cost and waitlists. Importantly, this work must be grounded in a neurodiversity-affirming approach that upholds the rights of autistic people to access high-quality, individualised supports. Lower-cost options should expand access and choice, not replace, restrict, or diminish existing supports. Within current system constraints, there is a critical opportunity to identify approaches that better support autistic people to navigate and benefit from available services, while also informing longer-term improvements to funding and service models. Strengthening the evidence base in this area will address community issues improving affordability while advancing equitable access to care.

Understanding the **impact of physical environments on autistic people** should be a priority for future research investment. The community highlighted how environmental factors, can significantly influence access, participation, wellbeing, and outcomes across settings including education and healthcare. Despite this, there is limited evidence to guide the design of environments that are consistently accessible and supportive. Strengthening the evidence base in this area would enable the development of practical, neurodiversity-affirming design principles that can be applied across sectors, improving inclusion while reducing preventable barriers to engagement.

Gender-based inequities were rarely examined directly. Gender inequities in education were not explicitly addressed in any recent Australian research (as determined by the title and abstract), despite being identified in research priority-setting papers. In mental and physical health, gender-

related experiences were contained in submissions to public consultations but received minimal empirical attention. The limited focus on gender highlights a broader need for intersectional and equity-informed research approaches that reflect the diversity of autistic people's lived experiences. At a minimum, this includes more consistent analysis and reporting of outcomes by gender and other key demographic characteristics (even if only in the supplementary materials of articles). This would help to ensure any inequities are visible, measurable and reported, so as to inform policy and practice into the future.

Collectively, these patterns indicate that equity-focused and structural dimensions of community concerns warrant stronger representation within the contemporary research landscape. This is also reflected in the limited and inconsistent reporting of participant demographics across empirical studies and, in some cases, research priority-setting exercises. Greater attention to comprehensive demographic reporting would enhance the capacity of the reader (including policymakers and service providers) to understand intersectional experiences and ensure that evidence used to inform policy reflects the diversity of autistic people across gender, culture, geography, support needs, and socioeconomic contexts.

5.2.2 Geographical gaps

Across categories, seven community-identified issues were not addressed in any of the 510 Australian empirical papers published between 2023 and 2025, including three within mental health. To assess whether these represented broader empirical gaps or location-specific gaps, recent international research (2023–2025) was examined. Six of the seven issues had been investigated internationally, indicating geographical gaps within the Australian evidence base. This included Aotearoa New Zealand research examining the highest-ranked housing and independent living issue: lack of suitable supported accommodation.

The only community-identified issue not addressed in either Australian or international research was the high cost of accessing mental health services (ranked third in the mental health category). This represents a substantive empirical knowledge gap. It is possible that cost issues are discussed within studies but not explicitly referenced in titles or abstracts; however, the absence of clearly identifiable research suggests limited direct investigation. While international evidence may inform understanding, Australian- and Aotearoa New Zealand-specific research remains essential to guide local service design, funding models, and policy implementation.

5.2.3 Research translation opportunities

In addition to empirical gaps, several research translation opportunities were identified. These represent areas where a body of research exists, yet the issue continues to be frequently raised in community consultations and/or identified in multiple research priority-setting studies.

A lack of autism awareness, understanding, and training among professionals was consistently raised across diagnosis, education, physical health services, mental health services, and the justice system. As noted in 5.2.1, although this issue is described in multiple recent studies, there is limited work demonstrating an effective way to improve knowledge and attitudes. Therefore, it remains a prominent concern in community submissions. This suggests that knowledge is developing and early stages to raise awareness could be translated, but the research is not yet at a level where it can be consistently embedded in practice, highlighting the need for stronger implementation, workforce development, and system-wide accountability mechanisms.

Similarly, issues relating to tailored and individualised service delivery were frequently examined in education, physical health, and mental health research. Despite this empirical attention, concerns about inconsistent, inflexible, or insufficiently individualised supports persist. This gap between evidence generation and lived experience points to an opportunity to strengthen research translation, implementation fidelity, and co-designed service reform.

5.2.4 Funding alignment and future research investment opportunities

The funding portfolio analysis provides insight into research investment patterns over time. By aligning funded grants with the community issues identified in public consultations, this analysis also allows examination of whether current patterns of research investment are likely to address the issues identified throughout this report.

In several areas, funding appeared well aligned with both community concerns and current research priorities. For example, grants were awarded to projects addressing delays in diagnosis, inadequacy of early intervention services, tailored educational supports, employment barriers, and individualised physical and mental health services. These areas were not only identified by the community as important, but also featured in research priority-setting studies and contemporary research outputs. Continued investment in these areas may therefore contribute to strengthening the evidence base and improving opportunities for future research translation.

However, several highly ranked community issues received little or no identifiable research investment. These included the high costs associated with diagnosis and physical and mental health services, environmental support requirements across education and healthcare settings, suitable supported accommodation, and gender-based inequities across multiple domains. In many cases, these issues were also identified as empirical knowledge gaps within the published literature, suggesting that they are currently underrepresented across both research activity and funding allocation.

The funding analysis also highlighted a potential broader pattern in which investment was more commonly directed towards interventions, services, and individual-level outcomes than towards structural and systems-level challenges. Community consultations repeatedly identified concerns relating to affordability, service navigation, workforce capability, environmental accessibility and system coordination. While some of these issues were examined in recent publications, they attracted comparatively little dedicated research funding. As a result, there is a risk that some of the most frequently reported barriers experienced by autistic people and their families will continue to receive limited empirical attention.

Importantly, the funding portfolio analysis can potentially provide an indication of the future research landscape. Unlike published research, which reflects work that has already been completed, funded grants represent areas in which new knowledge is likely to emerge over coming years. Examining funding allocation alongside published research therefore provides an indication of whether current investment patterns are likely to reduce existing knowledge gaps or whether gaps identified in this report may persist into the future.

Overall, these findings suggest that while there is evidence of alignment between some community priorities and research investment, opportunities remain to strengthen funding support for issues specific community issues reported but yet to be addressed. Greater attention to these areas may help ensure future research investment more closely reflects the issues shared by autistic people, families, and other stakeholders.

5.3 Population gaps: Demographic groups underrepresented in both community consultations and research priority-setting studies

This section examines who is contributing to community consultations and research priority-setting processes, and whether populations identified in the National Autism Strategy (NAS) are visible within these agenda-setting activities. Although the NAS priority groups are framed in relation to autistic people, they are applied here to all contributors in order to assess the overall diversity shaping research priorities.

Autistic people (38%, 40%) and family members or caregivers (43%, 49%) comprised the majority of contributors across both consultations and research priority-setting processes, respectively. This indicates substantial lived-experience involvement in agenda-setting. Caregiver perspectives were represented in similar proportions to autistic participants, suggesting that both groups play a significant role in shaping research priorities. This is fairly aligned with their representation as participants in research (37.1% of participants were autistic adults; 39.7% family members or caregivers). Other stakeholder groups showed more varied representation across the areas considered in this report. For example, teachers or other educational professionals made 15% of the submissions to public consultations but made up only 2.5% of participants in priority-setting exercises and 4.4% of participants in the research.

When examined against NAS priority groups (see Table 5.9), representation was uneven. Women and girls were the only group reported with sufficient frequency to allow confident assessment across both consultations and priority-setting processes. For other priority groups, including LGBTQIA+ people, culturally and linguistically diverse (CALD) and culturally and racially marginalised (CARM) communities, and young people, representation could be identified within one domain but not consistently across both, limiting the ability to assess overall visibility in agenda-setting activities. For several NAS priority groups, including gender diverse people, First Nations people, people with very high support needs, and older people, demographic reporting was insufficient or absent across both domains. In these cases, it is not possible to determine whether limited visibility reflects low participation or incomplete reporting practices.

Overall, the findings indicate that inconsistent demographic reporting significantly constrains the capacity to evaluate whether populations identified in national policy as at risk of inequity are proportionately represented in research planning processes. Strengthening demographic reporting within consultations and priority-setting activities would enhance transparency and support more equity-informed research agenda development.

Table 5.9: Demographic reporting across community consultations and priority-setting papers

NAS priority group	Consultations	Priority setting	Able to be examined across both consultation data and priority setting studies?
Women and girls	Reported (54%)	Reported (72%)	Yes
LGBTQIA+	Reported (11%)	Insufficient reporting	No
CALD and CARM	Reported (5.7%)	Insufficient reporting	No
Children and young people	Insufficient reporting	Reported (12%)	No
Gender diverse people	Insufficient reporting	Insufficient reporting	No
Indigenous people	Insufficient reporting	Insufficient reporting	No
Very high support needs	Not reported	Not reported	No
Older people	Not reported	Not reported	No

6. Alignment between autistic and autism community priorities and research activity: Aotearoa New Zealand

As seen in Section 1.7, some of the issues raised through consultation processes in Aotearoa New Zealand differed from those identified in Australian submissions. Accordingly, this section focuses specifically on the Aotearoa New Zealand context, drawing on (1) Aotearoa New Zealand community-identified priorities, (2) articulated research priorities in Aotearoa New Zealand, and (3) published autism research conducted within Aotearoa New Zealand.

Rather than merging findings across countries, alignment between Aotearoa New Zealand data was explored separately from the Australian data. The policy environment, education and health systems, funding structures, and cultural frameworks, including obligations under Te Tiriti o Waitangi, shape both the nature of community experiences and the direction of research activity in Aotearoa New Zealand. As such, community issues identified here are interpreted within their local social, cultural and institutional context.

6.1 Area-level exploration

This section therefore examines:

- key issues raised by the Aotearoa New Zealand autism community through formal consultation and sector processes
- Aotearoa New Zealand autism research priorities, and
- the scope, focus and patterns of autism research published by Aotearoa New Zealand-based researchers.

Maintaining this contextual focus allows for clearer identification of where Aotearoa New Zealand priorities align with, or diverge from, those observed in Australia, without collapsing distinct systems into a single narrative.

6.1.1 Diagnosis

Using the same alignment framework described for Australia, Table 6.1 shows strong alignment across community-identified issues, research priority-setting outputs, and published Aotearoa New Zealand research relating to “late, delayed, and fragmented diagnosis pathways” and “stereotyped and narrow diagnostic understanding as well as misdiagnosis and diagnostic confusion.”

Table 6.1: Alignment between community-identified issues related to experiences with diagnosis, Aotearoa New Zealand research priority-setting papers (2019–2025), and recent Aotearoa New Zealand empirical research (2023–2025)

Community Issue – Diagnosis	Aotearoa New Zealand research priority reports that prioritise this issue (Yes ✓ / No × number of reports identified in)	Aotearoa New Zealand research papers related to this issue (2023–2025) (Yes ✓ / No ×, number of papers on topic)	Aotearoa New Zealand funding addressing this issue (Yes ✓ / No ×, number and NZD$ value of grants on topic)
Late, delayed and fragmented diagnosis pathways	✓ 2	✓ 4	✓ 1 $159,500
High cost associated with private diagnosis (financial privilege)	× 0	× 0	× 0
Stereotyped and narrow diagnostic understanding as well as misdiagnosis and diagnostic confusion (especially for women, Māori and high-masking individuals)	✓ 2	✓ 2	× 0

Community relevance of diagnosis research. Of the eight papers categorised under diagnosis domain or 'other' (cross-domain), six were deemed to be describing or addressing community issues.

Key empirical knowledge gaps. The community issue "high cost associated with private diagnosis" is not evident in the research priority or published research. It is also not covered in the titles/abstracts of broader research literature from outside of Australia or Aotearoa New Zealand.

Research-translation gaps. Two key commonly identified community issues (late, delayed, and fragmented diagnosis pathways and stereotyped and narrow diagnostic understanding as well as misdiagnosis and diagnostic confusion) have aligned research papers, indicating these community issues persist despite research being published on the topic recently. This suggests that it is not being translated or changing the experiences within the community.

Funding alignment. Funding in the area of diagnosis was coded to one of three community-identified issues. One grant worth NZD $159,500 was coded to late, delayed and fragmented diagnosis pathways. No grants were coded to the remaining two community-identified issues, which related to the costs of private diagnosis and diagnostic bias and misdiagnosis, particularly for women, Māori, and high-masking individuals.

6.1.2 Early intervention and supports

Table 6.2 shows uneven alignment across community-identified issues, research priority-setting outputs, and published Aotearoa New Zealand research relating to early intervention and supports.

Table 6.2: Alignment between community-identified issues related to experiences with early intervention and supports, Aotearoa New Zealand research priority-setting papers (2019–2025), and recent Aotearoa New Zealand empirical research (2023–2025)

Community issue – Early intervention and supports	Aotearoa New Zealand research priority reports that prioritise this issue (Yes ✓ / No × number of reports identified in)	Aotearoa New Zealand research papers related to this issue (2023–2025) (Yes ✓ / No ×, number of papers on topic)	Aotearoa New Zealand funding addressing this issue (Yes ✓ / No ×, number and NZD$ value of grants on topic)
Lack of access to support following early identification	✓ 2	✓ 15	✓ 7 $3,749,540
Rigid eligibility criteria and crisis-based access; results in lack of coordination and needs-based support	✓ 2	× 0	✓ 1 $30,000
Limited lifespan and transition-focused support	✓ 1	✓ 9	× 0
Judgement and blame directed to parents	× 0	× 0	× 0

Note: Grants could be coded to a maximum of two community issues. As a result, a single grant may appear in more than one row. Grant counts and funding values represent the number and value of grants addressing each issue and should not be summed across rows to calculate overall totals.

Community relevance of early support research. Of the 24 papers categorised under early intervention and supports domain or 'other' (cross-domain), all were deemed to be describing or addressing community issues.

Key empirical knowledge gaps. The community issue "rigid eligibility criteria and crisis-based access; results in lack of coordination and needs-based support" was identified as a research priority in both Aotearoa New Zealand research priority-setting projects but not addressed in the published research. The community issue "judgement and blame directed to parents" is not evident in the research priority or published research.

Research-translation gaps. Two key commonly identified community issues (lack of access to support following early identification and limited lifespan and transition-focused support) have, respectively 15 and nine aligned research papers. This suggests a highly researched area that is not being translated into practice or into improving experiences within the community.

Funding alignment. Funding in the area of early identification and support was coded to two of four

community-identified issues. Seven grants worth NZD $3.75 million were coded to access to support following early identification. One grant worth NZD $30,000 was coded to eligibility criteria, service coordination, and needs-based support. No grants were coded to the remaining two issues: lifespan and transition support, and judgement and blame directed to parents.

6.1.3 Education

Table 6.3 shows community-identified issues relating to education have been identified as a research priority, and limited research has addressed these issues.

Table 6.3: Alignment between community-identified issues related to experiences with education, Aotearoa New Zealand research priority-setting papers (2019–2025), and recent Aotearoa New Zealand empirical research (2023–2025)

Community issue – Education	Aotearoa New Zealand research priority reports that prioritise this issue (Yes ✓ / No × number of reports identified in)	Aotearoa New Zealand research papers related to this issue (2023–2025) (Yes ✓ / No ×, number of papers on topic)	Aotearoa New Zealand funding addressing this issue (Yes ✓ / No ×, number and NZD$ value of grants on topic)
Lack of autism understanding and training across educators and leadership	✓ 2	✓ 3	× 0
Mainstream education environments are not autism inclusive (lack of sensory- and communication-accessible environments)	✓ 1	✓ 1	× 0
Systemic exclusion and unlawful disciplinary practices	× 0	✓ 1	× 0
Severe funding and resourcing gaps including rigid eligibility criteria	✓ 1	× 0	× 0

Community relevance of education research. Of the six papers categorised under education or 'other' (cross-domain), five were deemed to be describing or addressing community issues.

Key empirical knowledge gaps. The community-identified issue "severe funding and resourcing gaps including rigid eligibility criteria" was not addressed in the published research.

Research-translation gaps. While several studies addressed "lack of autism understanding and training across educators and leadership," more research is needed to also support translation to practice.

Funding alignment. No funding was coded to community-identified issues in the area of education.

6.1.4 Employment

Table 6.4 shows community-identified issues relating to employment have not been identified as a research priority, and very little research has addressed these issues.

Table 6.4: Alignment between community-identified issues related to experiences with employment, Aotearoa New Zealand research priority-setting papers (2019–2025), and recent Aotearoa New Zealand empirical research (2023–2025)

Community issue – Employment	Aotearoa New Zealand research priority reports that prioritise this issue (Yes ✓ / No ×, number of reports identified in)	Aotearoa New Zealand research papers related to this issue (2023–2025) (Yes ✓ / No ×, number of papers on topic)	Aotearoa New Zealand funding addressing this issue (Yes ✓ / No ×, number and NZD$ value of grants on topic)
Lack of inclusive practices and workplace accommodations	× 0	✓ 2	× 0
Inadequate employment support systems (employment support services; Work and Income)	× 0	✓ 1	× 0
Employment exclusion and discrimination despite capability (pressure to mask)	× 0	× 0	× 0
Flow-on impacts on whānau and caregiver employment	× 0	× 0	× 0

Community relevance of employment research. Of the five papers categorised under employment or 'other' (cross-domain), three were deemed to be describing or addressing community issues.

Key empirical knowledge gaps. The community-identified issues "employment exclusion and discrimination despite capability" and "flow-on impacts on whānau and caregiver employment" were not addressed in the research priority or published research.

Research-translation gaps. While a few studies addressed "lack of inclusive practices and workplace accommodations" and "inadequate employment support systems," more research is needed to also support translation to practice.

Funding alignment. No funding was coded to community-identified issues in the area of employment.

6.1.5 Housing and independent living

Table 6.5 shows community-identified issues relating to housing and independent living have not been identified as a research priority, and very little research has addressed these issues.

Table 6.5: Alignment between community-identified issues related to experiences with housing and independent living, Aotearoa New Zealand research priority-setting papers (2019–2025), and recent Aotearoa New Zealand empirical research (2023–2025)

Community issue – Housing and independent living	Aotearoa New Zealand research priority reports that prioritise this issue (Yes ✓ / No ×, number of reports identified in)	Aotearoa New Zealand research papers related to this issue (2023–2025) (Yes ✓ / No ×, number of papers on topic)	Aotearoa New Zealand funding addressing this issue (Yes ✓ / No ×, number and NZD$ value of grants on topic)
Shortage of suitable housing options (choice and control)	× 0	✓ 2	× 0
Forced dependence on family	× 0	× 0	× 0
Housing is a critical issue for autistic adults	× 0	× 0	× 0

Community relevance of housing and independent living research. Only two papers were categorised under housing and independent living or 'other' (cross-domain), both of which were deemed to be describing or addressing community issues.

Key empirical knowledge gaps. The community-identified issues "forced dependence on family" and "housing is a critical issue for autistic adults" were not addressed in the research priority or published research.

Research-translation gaps. While two studies addressed "shortage of suitable housing options," more research is needed to also support translation to practice.

Funding alignment. No funding was coded to community-identified issues in the area of housing and independent living.

6.1.6 Justice system

Table 6.6 shows limited alignment between community-identified issues relating to the justice system, research priority outputs, and published research.

Table 6.6: Alignment between community-identified issues related to experiences with justice system, Aotearoa New Zealand research priority-setting papers (2019–2025), and recent Aotearoa New Zealand research (2023–2025)

Community issue – Justice system	Aotearoa New Zealand research priority reports that prioritise this issue (Yes ✓ / No ×, number of reports identified in)	Aotearoa New Zealand research papers related to this issue (2023–2025) (Yes ✓ / No ×, number of papers on topic)	Aotearoa New Zealand funding addressing this issue (Yes ✓ / No ×, number and NZD$ value of grants on topic)
Lack of autism understanding and training among professionals in the justice system	✓ 1	✓ 1	× 0
Risk of harm from inadequately trained staff (e.g., masking, meltdowns, etc.)	× 0	× 0	× 0

Community relevance of justice system research. Only two papers were categorised under the justice system or the 'other' (cross-domain) category, one of which was deemed to be describing or addressing community issues.

Key empirical knowledge gaps. The limited research suggests empirical knowledge gaps relating to the criminal justice system.

Research-translation gaps. While one study addressed "lack of understanding and training among professionals in the justice system," more research is needed to also support translation to practice.

Funding alignment. No funding was coded to community-identified issues related to the justice system.

6.1.7 Physical health services

Table 6.7 shows that while community-identified issues are aligned with research priority outputs, little published research has addressed these issues.

Table 6.7: Alignment between community-identified issues related to experiences with physical health services, Aotearoa New Zealand research priority-setting papers (2019–2025), and recent Aotearoa New Zealand empirical research (2023–2025)

Community issue – Physical health	Aotearoa New Zealand research priority reports that prioritise this issue (Yes ✓ / No × number of reports identified in)	Aotearoa New Zealand research papers related to this issue (2023–2025) (Yes ✓ / No ×, number of papers on topic)	Aotearoa New Zealand funding addressing this issue (Yes ✓ / No ×, number and NZD$ value of grants on topic)
Lack of autism understanding and training among health professionals	✓ 1	× 0	✓ 1 $1,399,779
Autistic people are not believed or taken seriously	✓ 1	× 0	× 0
Clinical health settings are not autism inclusive (lack of sensory- and communication-accessible environments)	✓ 2	✓ 1	✓ 1 $25,315

Community relevance of physical health research. Of the 11 papers categorised under the physical health services or 'other' (cross-domain), only one was deemed to be describing or addressing community issues. This suggests empirical research in this area is not addressing community-identified issues.

Key empirical knowledge gaps. Although the research priority outputs address community-identified issues relating to physical health services, only one study addresses the issues, suggesting empirical knowledge gaps relating to physical health services.

Research-translation gaps. While one study addressed "clinical health settings are not autism inclusive," more research is needed to also support translation to practice.

Funding alignment. Funding in the area of physical health was coded to two of three community-identified issues. One grant worth NZD $1.40 million was coded to autism understanding and training among health professionals, and one grant worth NZD $25,315 was coded to autism-inclusive health settings. No grants were coded to the remaining issue, being believed and taken seriously.

6.1.8 Mental health services

Table 6.8 shows uneven alignment between community-identified issues, research priority outputs, and the published research.

Table 6.8: Alignment between community-identified issues related to experiences with mental health services, Aotearoa New Zealand research priority-setting papers (2019–25), and recent Aotearoa New Zealand empirical research (2023–2025)

Community issue – Physical health	Aotearoa New Zealand research priority reports that prioritise this issue (Yes ✓ / No × number of reports identified in)	Aotearoa New Zealand research papers related to this issue (2023–2025) (Yes ✓ / No ×, number of papers on topic)	Aotearoa New Zealand funding addressing this issue (Yes ✓ / No ×, number and NZD$ value of grants on topic)
Lack of autism understanding and training among mental health professionals	✓ 2	✓ 1	× 0
Lack of access to suitable mental health care	✓ 2	✓ 1	× 0
Risk of harm from inadequately trained staff (e.g., masking, meltdowns, etc.)	× 0	× 0	× 0
Lack of support for whānau and caregivers	× 0	✓ 5	✓ 2 $733,558

Community relevance of mental health research. Of the nine papers categorised under mental health services or 'other' (cross-domain), seven were deemed to be describing or addressing community issues.

Key empirical knowledge gaps. No research priority outputs or published research addressed the community issue "risk of harm from inadequately trained staff".

Research-translation gaps. Most (5 studies) of the mental health research studies addressed the community issue "lack of support for whānau and caregivers," indicating a well-researched area that is not being translated into practice or improving experiences within the community.

Funding alignment. Funding in the area of mental health was coded to one of four community-identified issues. Two grants worth NZD $733,558 were coded to support for whānau and caregivers. No grants were coded to the remaining three issues: autism understanding and training among mental health professionals, access to appropriate mental health care, and risk of harm from inadequately trained staff.

6.1.9 Other and emerging or cross-area themes

Table 6.9 shows alignment between other and emerging or cross-domain themes and research priorities, but little research addressing the themes.

Table 6.9: Alignment between community-identified issues related to experiences with other/emerging themes, Aotearoa New Zealand research priority-setting papers (2019–2025), and recent Aotearoa New Zealand empirical research (2023–2025)

Community Issue – Other emerging or cross-domain themes	Aotearoa New Zealand research priority reports that prioritise this issue (Yes ✓ / No ×, number of reports identified in)	Aotearoa New Zealand research papers related to this issue (2023–2025) (Yes ✓ / No ×, number of papers on topic)	Aotearoa New Zealand funding addressing this issue (Yes ✓ / No ×, number and NZD$ value of grants on topic)
Limitations of the Disability Support System (DSS)	× 0	× 0	× 0
A lack of resources in regional, rural, and remote areas	× 0	× 0	✓ 1 $99,966
Challenges related to government support and systems (lack of coordination, inadequate funding)	✓ 1	× 0	✓ 1 $124,442
Lack of autistic-led advocacy or leadership	✓ 1	✓ 2	✓ 1 $29,071
Lack of resources for autistic adults and across the lifespan (limited supports and transition supports, lifelong care)	✓ 1	× 0	× 0
Intersectional barriers and issues	✓ 1	✓ 1	✓ 6 $823,808

Note: Grants could be coded to a maximum of two community issues. As a result, a single grant may appear in more than one row. Grant counts and funding values represent the number and value of grants addressing each issue and should not be summed across rows to calculate overall totals.

Community relevance of other/emerging research. Of the five papers categorised under other/emerging areas, three were deemed to be describing or addressing community issues.

Key empirical knowledge gaps. Very limited research addressed other and emerging or cross-domain themes, suggesting empirical knowledge gaps across these areas.

Research-translation gaps. While two studies addressed "lack of autistic-led advocacy or leadership," more research is needed to also support translation to practice.

Funding alignment. Funding was coded to four of six "other" or cross-domain community-identified issues. The largest amount of funding and highest number of grants were coded to intersectional barriers and issues, with six grants worth NZD $823,808. One grant worth NZD $124,442 was coded

to government support and system coordination, one grant worth NZD $99,966 was coded to regional, rural, and remote resources, and one grant worth NZD $29,071 was coded to autistic-led advocacy and leadership. No grants were coded to limitations of the disability support system or resources for autistic adults and across the lifespan.

6.2 Summary of alignment

Two research priority-setting projects and relatively limited empirical research across domains exist for Aotearoa New Zealand.

6.2.1 Community relevance of Aotearoa New Zealand autism research

There was a total of 71 empirical research studies from Aotearoa New Zealand (primary author and/or New Zealand participants). Of these, 53 (75%) studies directly addressed identified community issues and/or research priorities.

6.2.2 Empirical knowledge gaps: Community issues not covered in research

The following Aotearoa New Zealand community research priorities were not identified in the published research:

- quality of life of autistic people
- perspective of autistic people with diverse support needs
- experience across the lifespan
- cognitive thinking and learning styles of autistic people
- co-ordination and co-operation of supports and services.

While empirical research in Aotearoa New Zealand is addressing factors related to the causes and health of autistic people, it is not addressing community-identified issues related to physical health services. Community-identified issues or research priorities in employment, housing and independent living, and the justice system are also currently being addressed by only very limited research activity.

6.2.3 Geographical gaps: Community issues not covered Aotearoa New Zealand autism research but covered elsewhere

Although Aotearoa New Zealand research is not focussed on the above topics, published Australian research does explore quality of life of autistic people, perspectives of autistic people with diverse support needs, autistic people's experience across the lifespan, cognitive thinking and learning styles of autistic people, and co-ordination and co-operation of supports and services, at least to some degree. However, non-Aotearoa New Zealand research on co-ordination and co-operation of supports and services may have limited applicability to the Aotearoa New Zealand setting.

6.2.4 Research-translation gaps: Research exists but community continues to report issues

For the Aotearoa New Zealand data there were three key areas where research evidence exists, but communities continue to report persistent problems, suggesting limited policy or practice uptake. These relate to: (1) Mental health – lack of support for whānau and caregivers, (2) Early support or intervention – lack of access to support following early identification, and (3) Early support or intervention – limited lifespan and transition-focused support.

6.2.5 Population gaps: Demographic groups underrepresented in both community consultations and research priority-setting studies

Pasifika and male demographic groups are underrepresented in Aotearoa New Zealand community consultations and research priority-setting processes. Further, similar to the Australian data, limited data exist for intersectional groups such as those with complex support and/or communication needs.

6.2.6 Funding alignment and future research investment

The Aotearoa New Zealand funding portfolio was also coded against the community issue framework where there was clear and direct alignment. This provides an indication of whether current funding patterns are likely to address the community-identified issues described in this report. As with Australia, funding was unevenly distributed across community issues, with some areas attracting investment while others, including several highly ranked community concerns, received little or no identifiable funding including housing, improved mental health care and employment.

7. Keeping this report updated

This report brings together four related but distinct evidence sources: community-identified issues, research priority-setting studies, published autism research, and research funding data. This document has provided a baseline review of these areas, but this is just the start. This document should be treated as a baseline, upon which further reviews be compared. To undertake future reviews, it is important to consider that each source changes at different rates and therefore require different levels of resourcing to update. A single update cycle is therefore unlikely to be appropriate for all sections. Therefore a tiered update model is recommended. Under this model, sections that are likely to change more frequently, such as research priority-setting studies, would be monitored more often. Sections that require large-scale data extraction and coding, such as community consultation analysis and full published literature mapping, would be updated less frequently, unless a major policy or consultation process creates a clear reason for earlier review.

7.1 Community-identified issues

The community issues section should be fully updated approximately every five years, or earlier if a major national, state, territory, or Aotearoa New Zealand consultation process occurs. This includes major autism strategies, disability system reforms, parliamentary inquiries, national roadmaps, or other formal public consultation processes that invite the Autistic or autism community to submit responses through a formal process.

A five-year update cycle is appropriate because this section relies on large-scale consultation data and a detailed audit against the categories. These submissions are not produced continuously, and meaningful changes in community-identified issues are most likely to be visible after major consultations, policy or system changes. Each update should document which consultation sources were included, who contributed (where demographic information is available), how the audit against the categories was conducted, and whether any new issue categories were added.

7.2 Research priority-setting studies

The research priorities section should be monitored annually. Each year, the search strategy should be re-run to identify new peer-reviewed papers, reports, grey literature, conference outputs, or community-led priority-setting work from Australia and Aotearoa New Zealand.

Where new eligible studies or reports are identified, these should be screened, extracted, quality assessed where relevant, and incorporated into an updated synthesis. Where no new eligible evidence is identified, this should be recorded in a “What’s new” note. The review methods and protocol should be reviewed every one to two years to check whether the scope, inclusion criteria, search strategy, or analysis approach remain appropriate.

This approach is more feasible than a living systematic review, which would require regular monthly searching and ongoing incorporation of evidence. Annual searching provides a practical balance between maintaining currency and managing resources.

7.3 Published autism research

The published literature section should have a full systematic update every five years. There could be an optional light scan every two years to identify whether the research landscape is changing in ways that would warrant an earlier update.

A full update should repeat the database searches, screening, coding, and demographic reporting analysis used in the original report, with new keywords or search terms if terminology changes. The update should retain enough consistency with the original coding framework to allow comparison over time, while also allowing new categories to be added if the research landscape has changed. Interim scans should not replace the full systematic update. Their purpose would be to identify major changes in volume, focus, or emerging areas of research.

7.4 Funding portfolio analysis

The funding portfolio analysis should be updated every three to five years, depending on the availability of grant data and the intended use of the report. If the analysis is intended to inform funding accountability or near-term funding strategy, a three-year cycle would be preferable. If it is intended as a broad landscape review, a five-year cycle would be sufficient.

Each update should extract newly awarded grants from the relevant funding databases and code them against the current community issue framework. Coding should remain conservative; grants should only be coded as aligned with a community issue where the funded activity directly addresses that issue, rather than relying on broad claims about possible future benefit. Where grants do not clearly align with a community priority, they should be coded as having no clear alignment.

7.5 Alignment and gap analysis

The alignment and gap analysis should be updated after the relevant source sections have been refreshed. In most cases, this would occur every five years. Earlier updates may be warranted if there is a major change in one evidence source, such as a new national consultation, a major update to research priorities, or a substantial shift in funding patterns.

Each update should compare community issues, research priorities, published research, and funding allocation using a transparent and consistent framework. Where possible, the same indicators should be retained across versions to allow comparison over time. Any changes to coding categories, scoring rules, or inclusion criteria should be documented clearly.

7.6 Governance and version control

Each update should include clear version control, including the date of the update, sections updated, sources searched, eligibility criteria, coding framework, and any methodological changes. Previous versions should remain archived and citable. Updates should also include a brief “What changed?” summary so that readers can see whether new evidence has altered the interpretation of community priorities, research gaps, translation opportunities, or funding alignment.

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Appendix A

Development of empirical knowledge gap and research translation scores

To support a systematic and transparent identification of priority areas across the research landscape, two composite scores were developed: (1) an Empirical Knowledge Gap Score and (2) a Research Translation Opportunity Score. These scores were designed to complement narrative analysis and enable structured comparison across community-identified issues.

Empirical knowledge gap score

The Empirical Knowledge Gap Score was developed to identify issues that are highly prioritised by the community but remain under-examined in recent empirical research.

Three components were included:

1. Community ranking of the issue (with higher-ranked issues weighted more strongly)
2. Number of research priority-setting publications identifying the issue (greater endorsement indicating higher recognised importance), and
3. Number of recent empirical research papers (2023–2025) addressing the issue (fewer papers indicating a larger potential gap).

Each component was standardised to a 0–1 scale to ensure equal contribution to the overall score. Community rank was scaled relative to the maximum observed rank (9) to allow comparability across categories with differing numbers of issues. Priority-setting counts were scaled against the maximum possible value (6). Empirical research counts were reverse-scaled relative to the maximum observed value (14), such that issues addressed in fewer studies received higher gap scores. The three standardised components were averaged to produce a final score.

Under this approach, higher scores indicate issues that are:

- ranked highly by the community
- consistently identified in priority-setting processes, and
- minimally addressed in recent empirical research.

This provides a structured indicator of relative research need across categories.

Research translation opportunity score

A parallel scoring system was developed to identify issues that may be positioned for research translation. In contrast to the knowledge gap score, this metric was designed to highlight issues where strong community concern aligns with an existing body of empirical evidence.

The same three components were included:

1. Community ranking
2. Number of priority-setting publications identifying the issue, and
3. Number of recent empirical research papers addressing the issue (2023–2025).

All components were standardised to a 0–1 scale to ensure equal weighting. Community rank was reverse-scaled so that higher-ranked issues received higher values. Priority-setting and empirical research counts were scaled relative to their respective maximum observed values. The three standardised components were averaged to produce the final score.

Higher scores therefore indicate issues that are:

- highly ranked in community consultations,
- endorsed across multiple priority-setting exercises, and
- supported by a comparatively substantial recent evidence base.

These issues represent areas where community concern persists despite available research, suggesting potential opportunities for strengthened knowledge translation, implementation, or system-level uptake

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