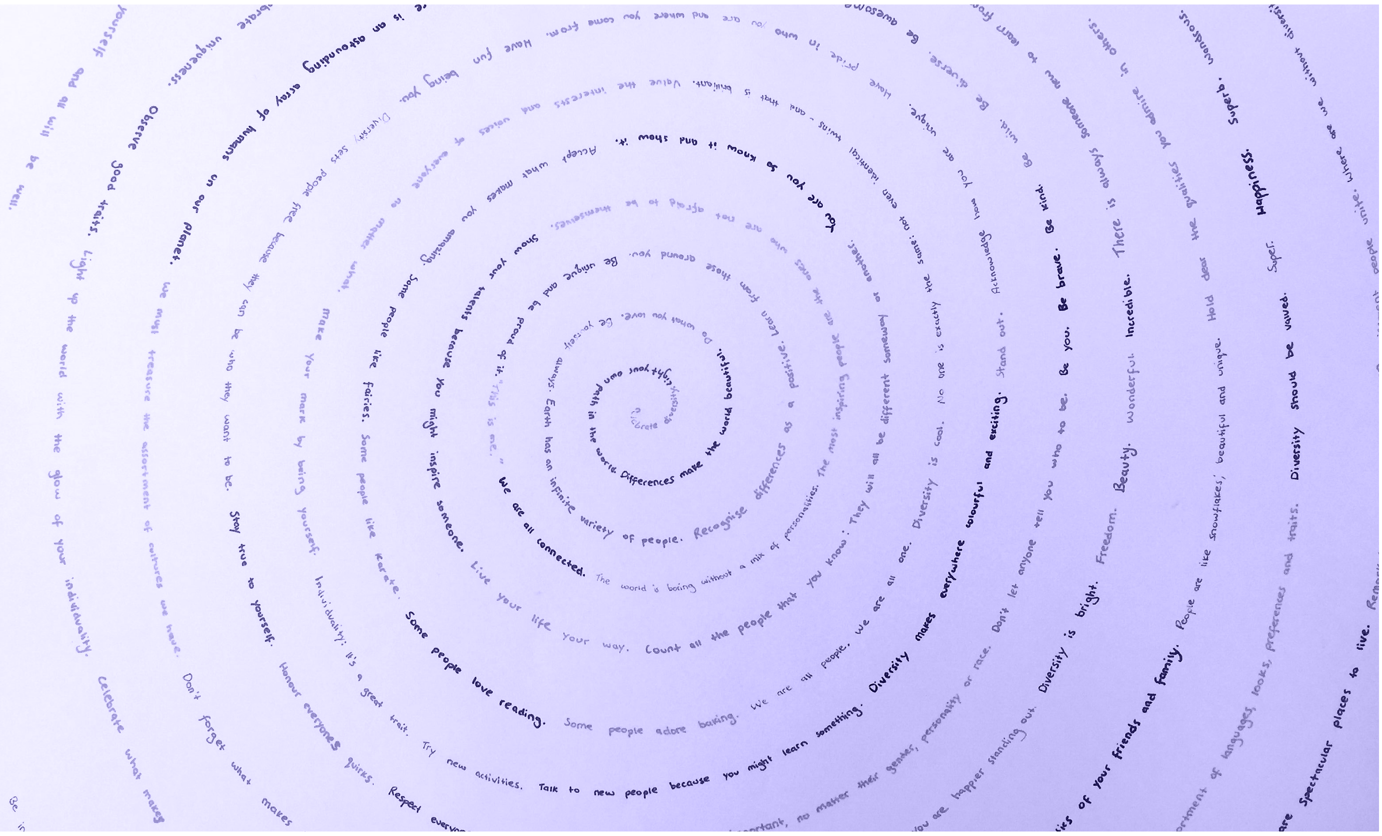
Research evidence, policy and landscape mapping to inform the National Autism Strategy

Appendices

Dawn Adams, Sonya Girdler, Stephanie Malone, Wenn Lawson, Annette Carroll, Ocean Colville, Kate Simpson, Emily D'Arcy, Emily Jackson, Lydia Timms, Valeska Berg, Patrice Whitehorne-Smith, Tanya Picen, Bahareh Afsharnejad

June 2023



autismcrc.com.au

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

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

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

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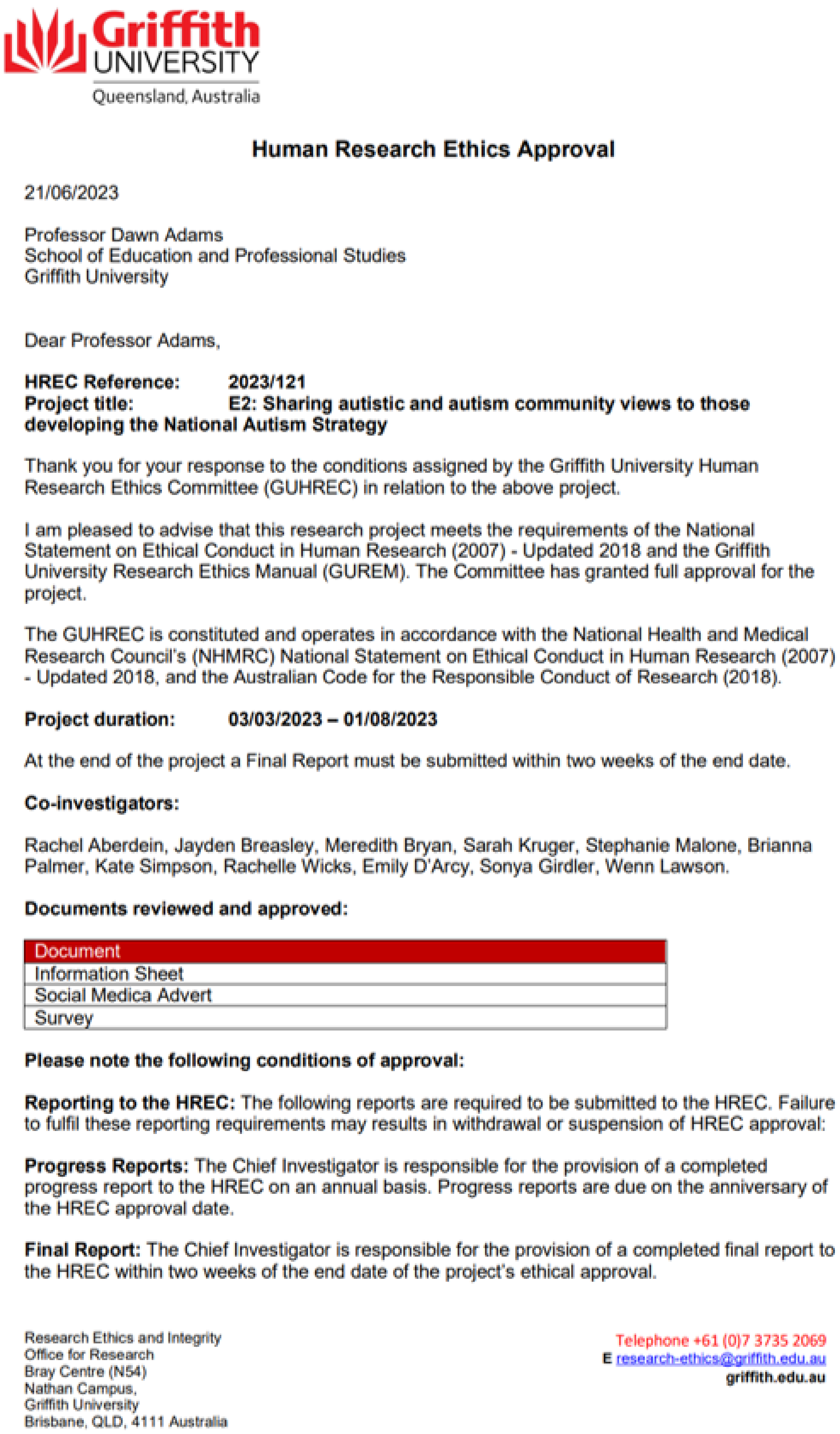
Appendix A: Ethical approval for survey



Griffith
UNIVERSITY
Queensland, Australia

Human Research Ethics Approval

21/06/2023

Professor Dawn Adams
School of Education and Professional Studies
Griffith University

Dear Professor Adams,

HREC Reference: **2023/121**
Project title: **E2: Sharing autistic and autism community views to those developing the National Autism Strategy**

Thank you for your response to the conditions assigned by the Griffith University Human Research Ethics Committee (GUHREC) in relation to the above project.

I am pleased to advise that this research project meets the requirements of the National Statement on Ethical Conduct in Human Research (2007) - Updated 2018 and the Griffith University Research Ethics Manual (GUREM). The Committee has granted full approval for the project.

The GUHREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) National Statement on Ethical Conduct in Human Research (2007) - Updated 2018, and the Australian Code for the Responsible Conduct of Research (2018).

Project duration: **03/03/2023 – 01/08/2023**

At the end of the project a Final Report must be submitted within two weeks of the end date.

Co-investigators:

Rachel Aberdein, Jayden Breasley, Meredith Bryan, Sarah Kruger, Stephanie Malone, Brianna Palmer, Kate Simpson, Rachelle Wicks, Emily D'Arcy, Sonya Girdler, Wenn Lawson.

Documents reviewed and approved:

Document
Information Sheet
Social Medica Advert
Survey

Please note the following conditions of approval:

Reporting to the HREC: The following reports are required to be submitted to the HREC. Failure to fulfil these reporting requirements may results in withdrawal or suspension of HREC approval:

Progress Reports: The Chief Investigator is responsible for the provision of a completed progress report to the HREC on an annual basis. Progress reports are due on the anniversary of the HREC approval date.

Final Report: The Chief Investigator is responsible for the provision of a completed final report to the HREC within two weeks of the end date of the project's ethical approval.

Research Ethics and Integrity
Office for Research
Bray Centre (N54)
Nathan Campus,
Griffith University
Brisbane, QLD, 4111 Australia

Telephone +61 (0)7 3735 2069
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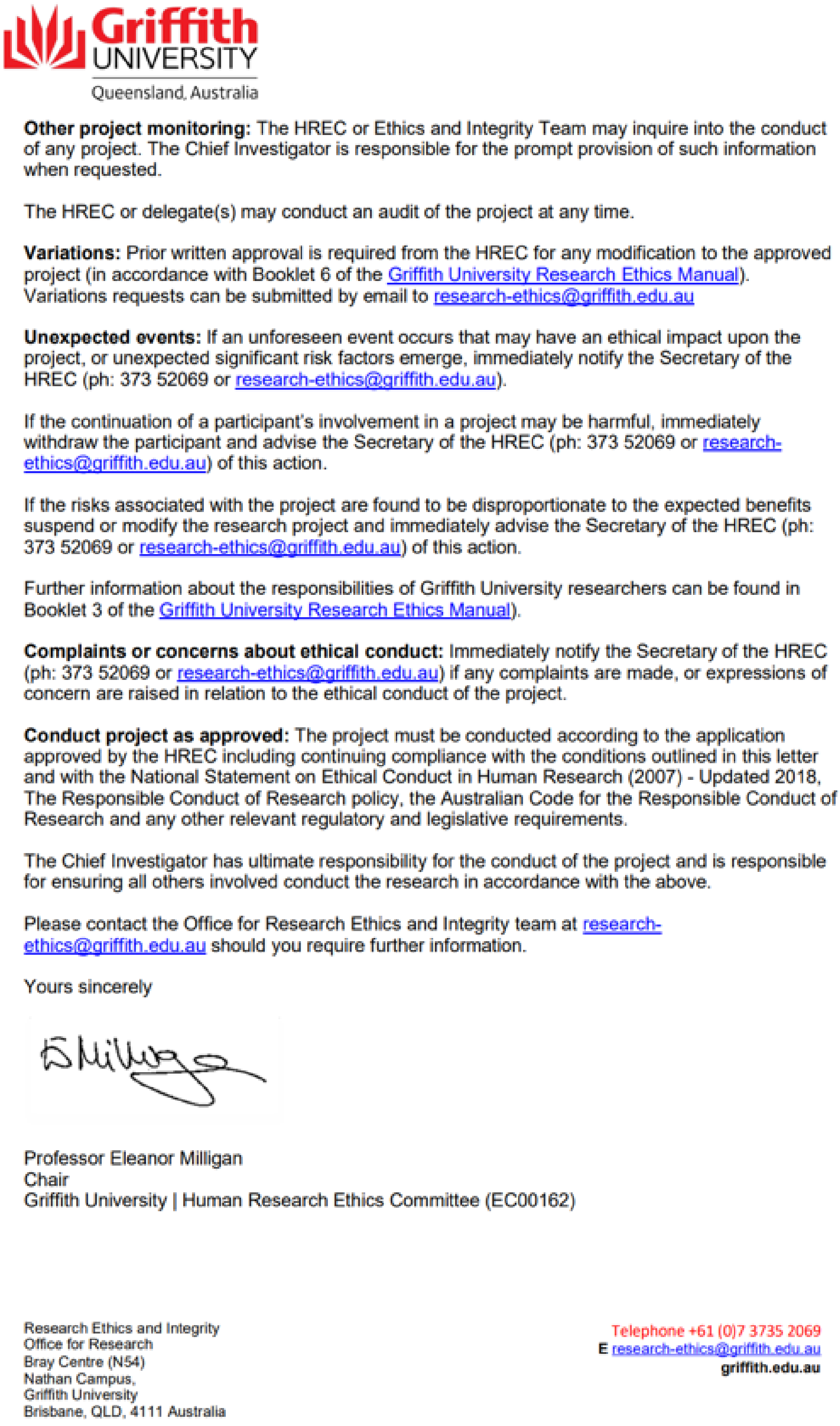

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Queensland, Australia

Other project monitoring: The HREC or Ethics and Integrity Team may inquire into the conduct of any project. The Chief Investigator is responsible for the prompt provision of such information when requested.

The HREC or delegate(s) may conduct an audit of the project at any time.

Variations: Prior written approval is required from the HREC for any modification to the approved project (in accordance with Booklet 6 of the Griffith University Research Ethics Manual). Variations requests can be submitted by email to research-ethics@griffith.edu.au

Unexpected events: If an unforeseen event occurs that may have an ethical impact upon the project, or unexpected significant risk factors emerge, immediately notify the Secretary of the HREC (ph: 373 52069 or research-ethics@griffith.edu.au).

If the continuation of a participant's involvement in a project may be harmful, immediately withdraw the participant and advise the Secretary of the HREC (ph: 373 52069 or research-ethics@griffith.edu.au) of this action.

If the risks associated with the project are found to be disproportionate to the expected benefits suspend or modify the research project and immediately advise the Secretary of the HREC (ph: 373 52069 or research-ethics@griffith.edu.au) of this action.

Further information about the responsibilities of Griffith University researchers can be found in Booklet 3 of the Griffith University Research Ethics Manual).

Complaints or concerns about ethical conduct: Immediately notify the Secretary of the HREC (ph: 373 52069 or research-ethics@griffith.edu.au) if any complaints are made, or expressions of concern are raised in relation to the ethical conduct of the project.

Conduct project as approved: The project must be conducted according to the application approved by the HREC including continuing compliance with the conditions outlined in this letter and with the National Statement on Ethical Conduct in Human Research (2007) - Updated 2018, The Responsible Conduct of Research policy, the Australian Code for the Responsible Conduct of Research and any other relevant regulatory and legislative requirements.

The Chief Investigator has ultimate responsibility for the conduct of the project and is responsible for ensuring all others involved conduct the research in accordance with the above.

Please contact the Office for Research Ethics and Integrity team at research-ethics@griffith.edu.au should you require further information.

Yours sincerely

Professor Eleanor Milligan
Chair
Griffith University | Human Research Ethics Committee (EC00162)

Research Ethics and Integrity
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Appendix B: Survey

Link to copy of the survey. Note this is not the link that was provided to the participants as that survey has now ended, but it is an exact replica of what the participants saw.

https://www151.griffith.edu.au/redcap/surveys/?s=NJHJHN4HN49DMTTP

Have your say: Informing the National Autism Strategy

What is this survey?

Autism CRC (with Griffith University, Curtin University and Wenn Lawson) are working with the Australian Government Department of Social Services (DSS) to understand the views of the community. This will help inform the National Autism Strategy.

It is important that autistic people, their families/carers and people who work with them have their say.

What will we ask you?

We would like to know community views and experiences on a range of topics. For each topic you want to comment on, we will ask you:

- The problems experienced by autistic people
- What you think is causing or leading to these problems
- What you think could be done to prevent or reduce these problems
- What you think is working well or has worked well

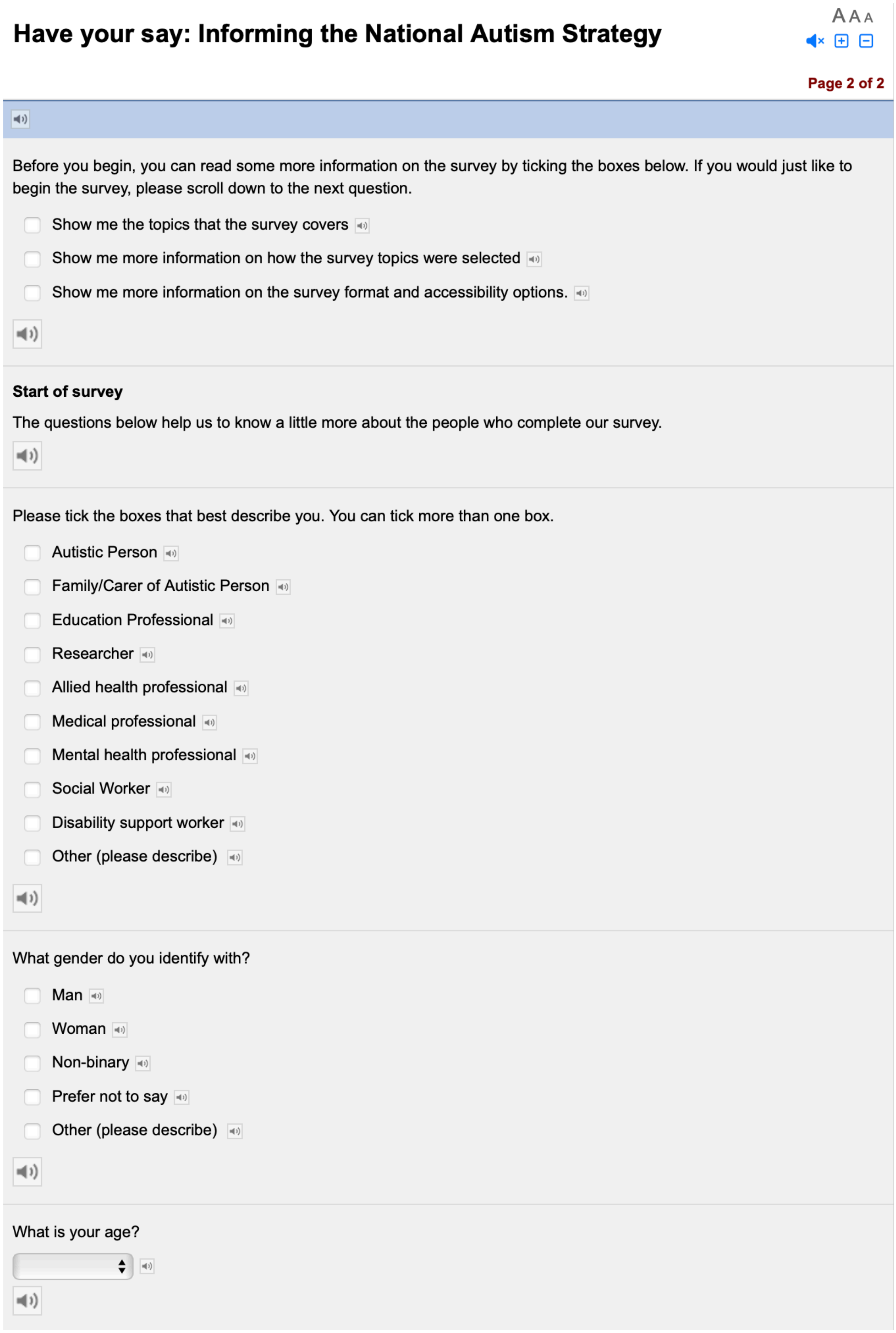
Once you have completed the questions on your chosen topics, we would then like to ask you

- what methods should be used to make sure everyone can have their say in the development of the National Autism Strategy
- some questions about you so that we can describe the group of people who completed this survey.

This project has been reviewed by Griffith University Human Research Ethics Committee (reference 2023/121). You can download, read or save the full information sheet below.

Pressing "next page" is taken as consent to take part in this research.

Attachment: Information sheet to read or download.pdf (0.18 MB)



Have your say: Informing the National Autism Strategy

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Before you begin, you can read some more information on the survey by ticking the boxes below. If you would just like to begin the survey, please scroll down to the next question.

- ☐ Show me the topics that the survey covers
- ☐ Show me more information on how the survey topics were selected
- ☐ Show me more information on the survey format and accessibility options.

Start of survey

The questions below help us to know a little more about the people who complete our survey.

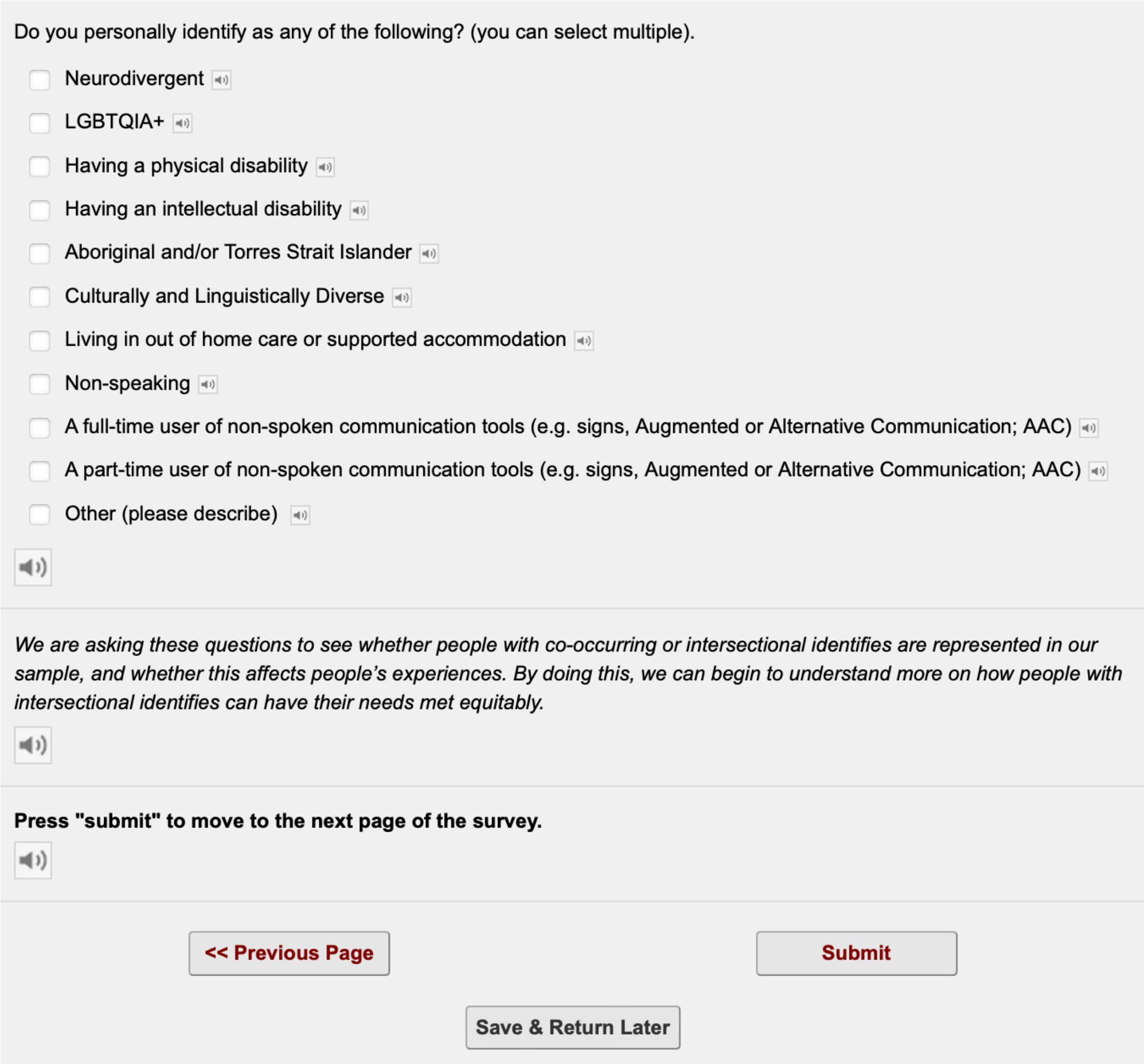
Please tick the boxes that best describe you. You can tick more than one box.

- ☐ Autistic Person
- ☐ Family/Carer of Autistic Person
- ☐ Education Professional
- ☐ Researcher
- ☐ Allied health professional
- ☐ Medical professional
- ☐ Mental health professional
- ☐ Social Worker
- ☐ Disability support worker
- ☐ Other (please describe)

What gender do you identify with?

- ☐ Man
- ☐ Woman
- ☐ Non-binary
- ☐ Prefer not to say
- ☐ Other (please describe)

What is your age?

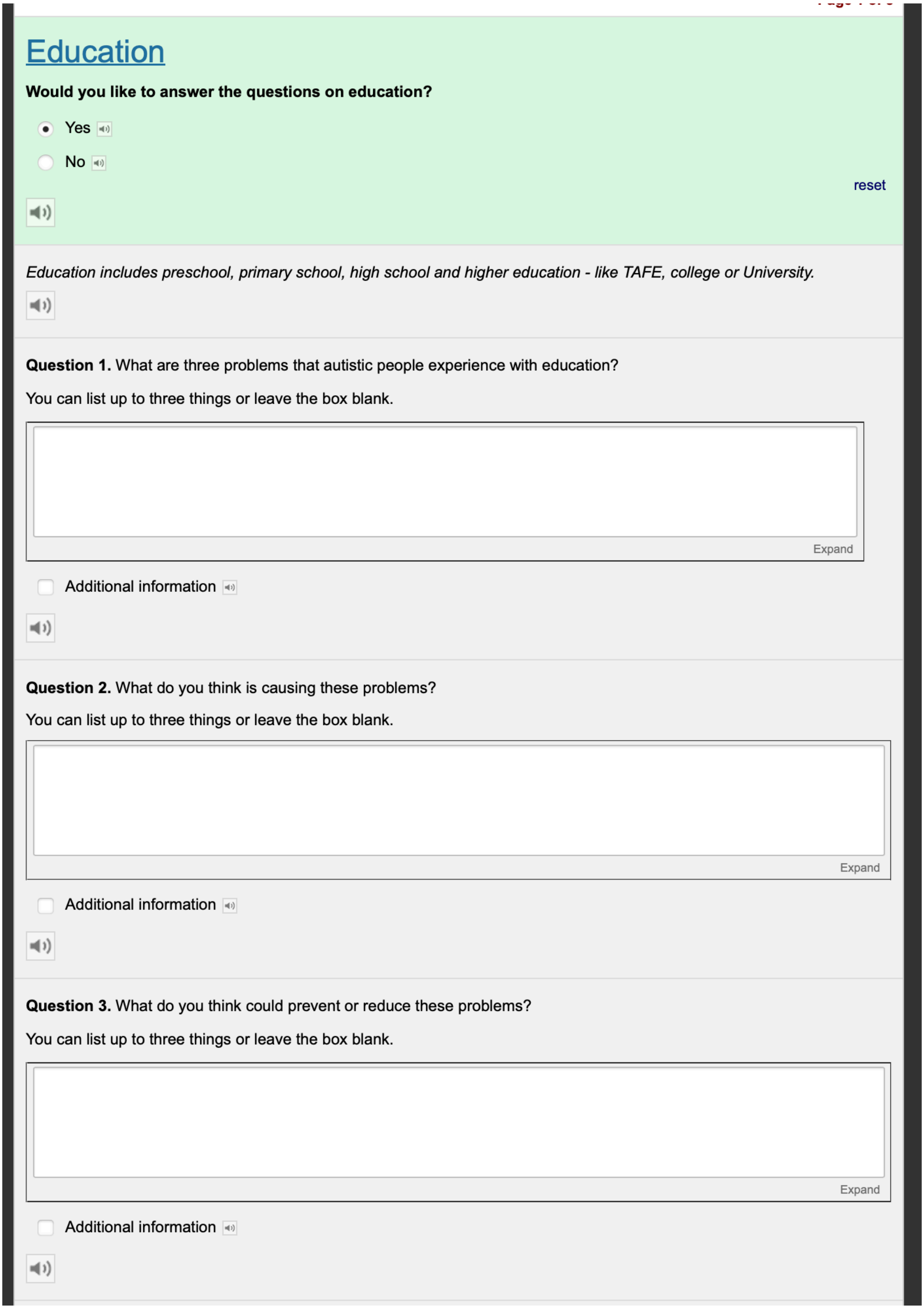


Do you personally identify as any of the following? (you can select multiple).

- ☐ Neurodivergent
- ☐ LGBTQIA+
- ☐ Having a physical disability
- ☐ Having an intellectual disability
- ☐ Aboriginal and/or Torres Strait Islander
- ☐ Culturally and Linguistically Diverse
- ☐ Living in out of home care or supported accommodation
- ☐ Non-speaking
- ☐ A full-time user of non-spoken communication tools (e.g. signs, Augmented or Alternative Communication; AAC)
- ☐ A part-time user of non-spoken communication tools (e.g. signs, Augmented or Alternative Communication; AAC)
- ☐ Other (please describe)

We are asking these questions to see whether people with co-occurring or intersectional identifies are represented in our sample, and whether this affects people's experiences. By doing this, we can begin to understand more on how people with intersectional identifies can have their needs met equitably.

Press "submit" to move to the next page of the survey.



Education

Would you like to answer the questions on education?

● Yes

○ No

Education includes preschool, primary school, high school and higher education - like TAFE, college or University.

Question 1. What are three problems that autistic people experience with education?

You can list up to three things or leave the box blank.

☐ Additional information

Question 2. What do you think is causing these problems?

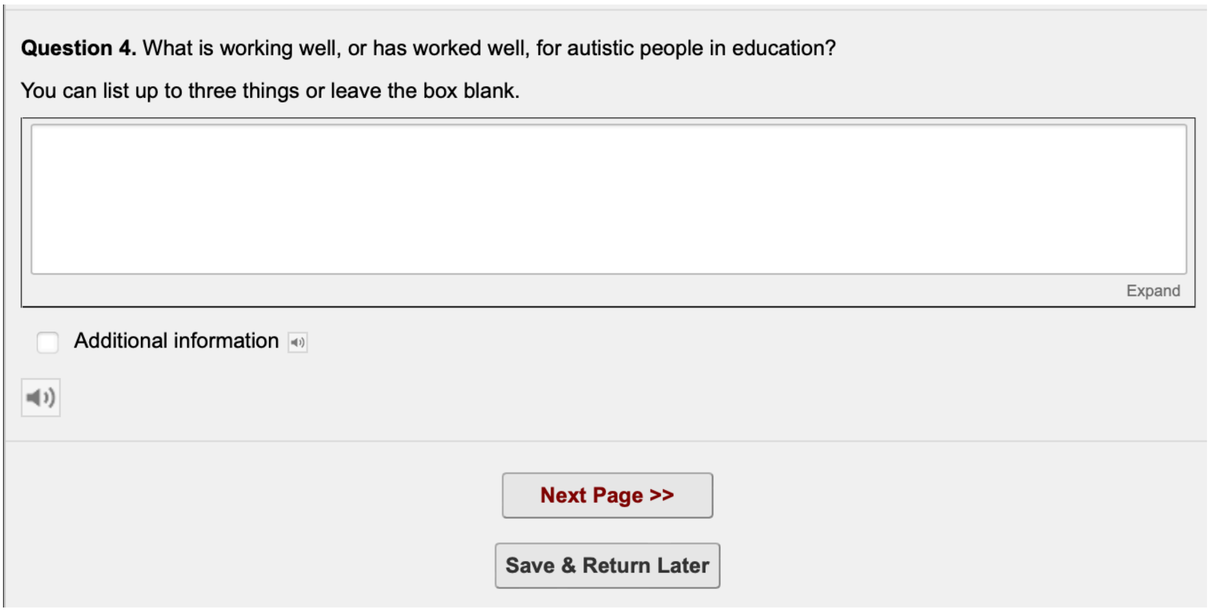
You can list up to three things or leave the box blank.

☐ Additional information

Question 3. What do you think could prevent or reduce these problems?

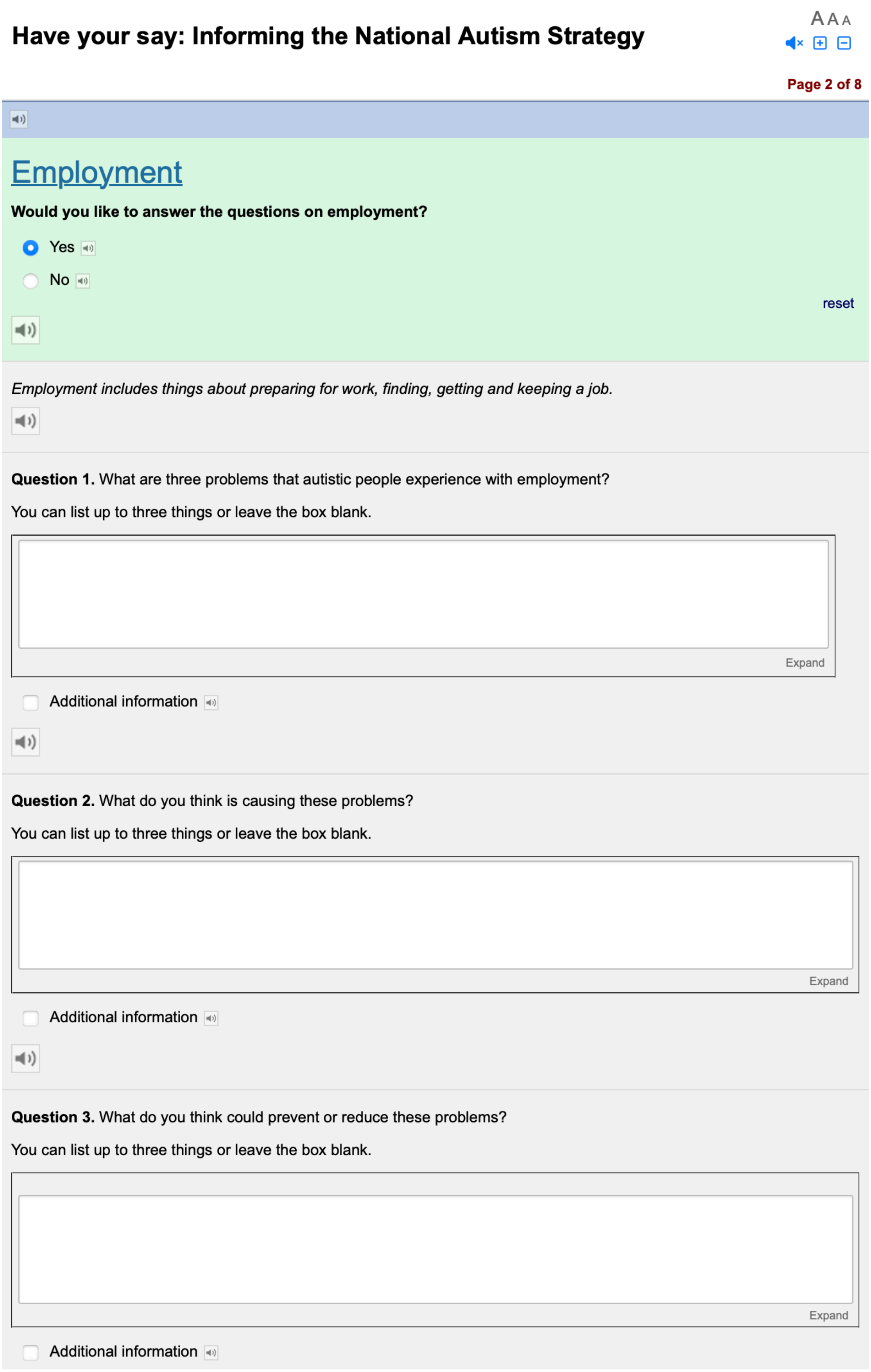
You can list up to three things or leave the box blank.

☐ Additional information



Question 4. What is working well, or has worked well, for autistic people in education?

You can list up to three things or leave the box blank.



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Employment

Would you like to answer the questions on employment?

● Yes

○ No

reset

Employment includes things about preparing for work, finding, getting and keeping a job.

Question 1. What are three problems that autistic people experience with employment?

You can list up to three things or leave the box blank.

☐ Additional information

Question 2. What do you think is causing these problems?

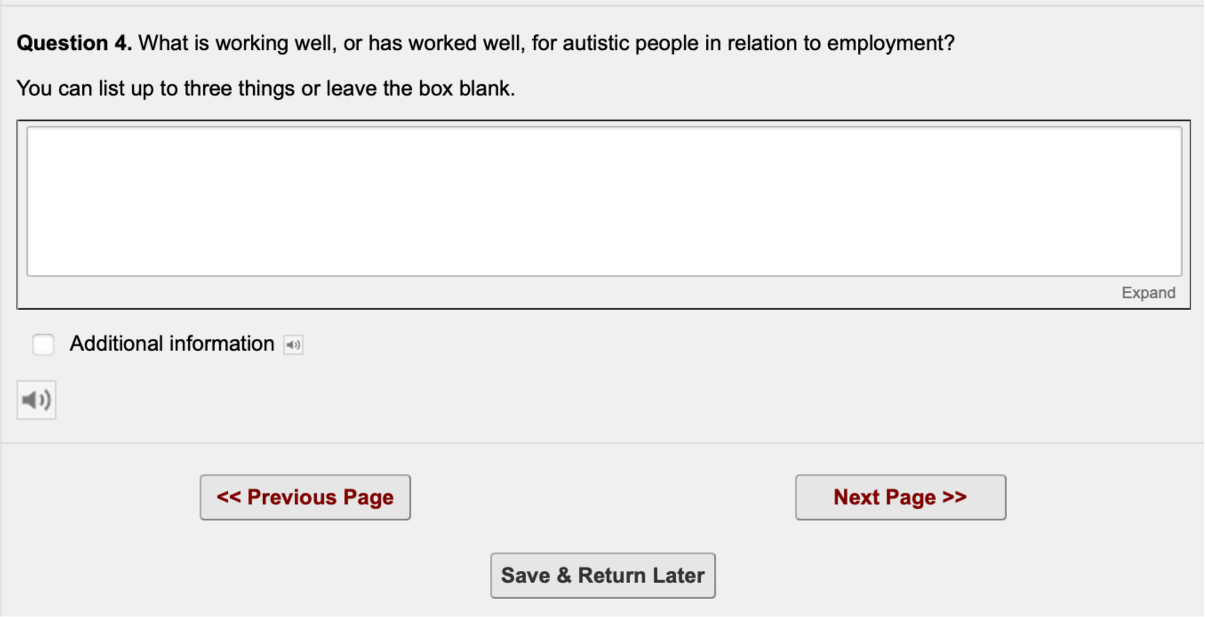
You can list up to three things or leave the box blank.

☐ Additional information

Question 3. What do you think could prevent or reduce these problems?

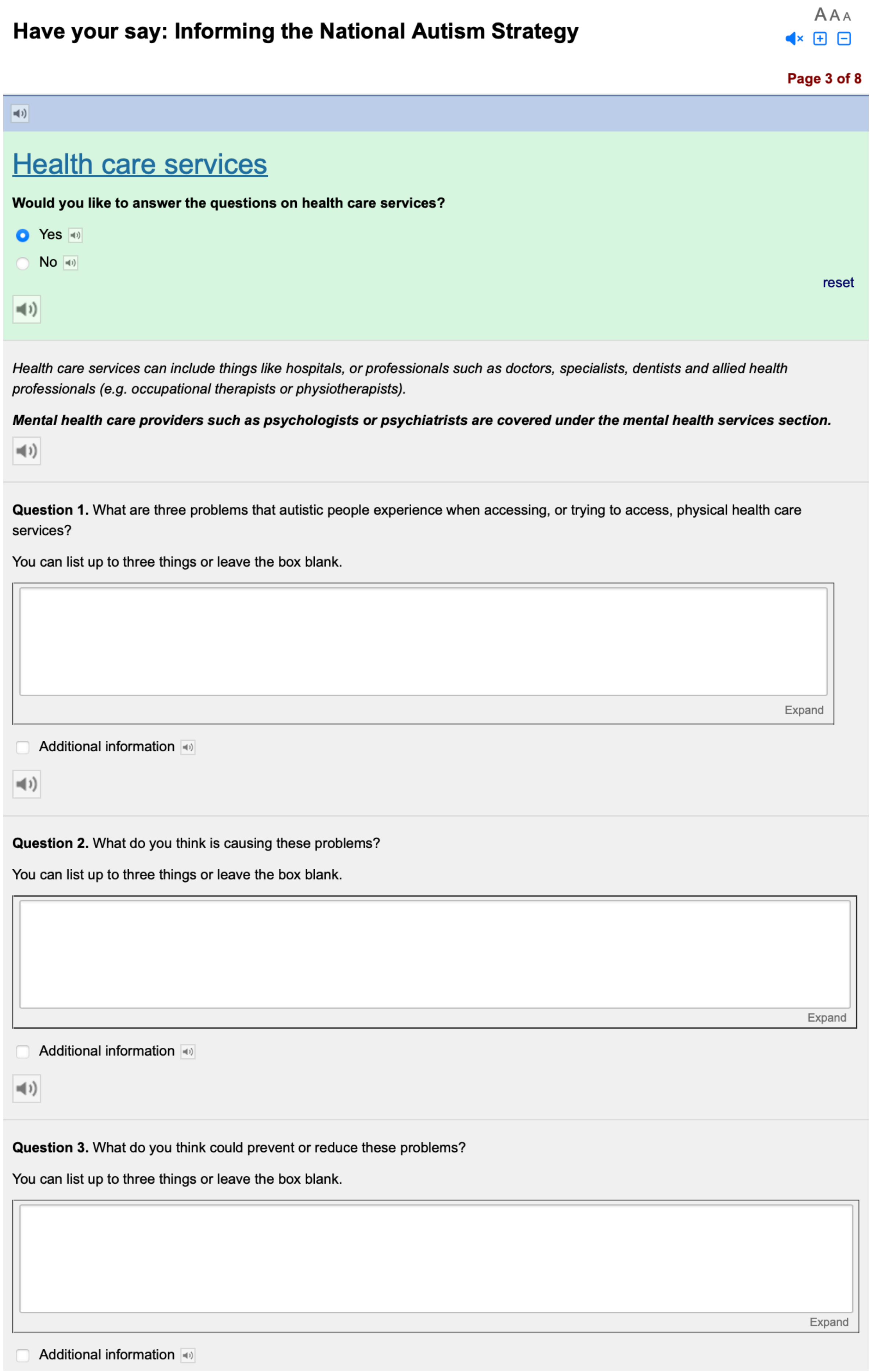
You can list up to three things or leave the box blank.

☐ Additional information



Question 4. What is working well, or has worked well, for autistic people in relation to employment?

You can list up to three things or leave the box blank.



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Health care services

Would you like to answer the questions on health care services?

● Yes

○ No

Health care services can include things like hospitals, or professionals such as doctors, specialists, dentists and allied health professionals (e.g. occupational therapists or physiotherapists).

Mental health care providers such as psychologists or psychiatrists are covered under the mental health services section.

Question 1. What are three problems that autistic people experience when accessing, or trying to access, physical health care services?

You can list up to three things or leave the box blank.

☐ Additional information

Question 2. What do you think is causing these problems?

You can list up to three things or leave the box blank.

☐ Additional information

Question 3. What do you think could prevent or reduce these problems?

You can list up to three things or leave the box blank.

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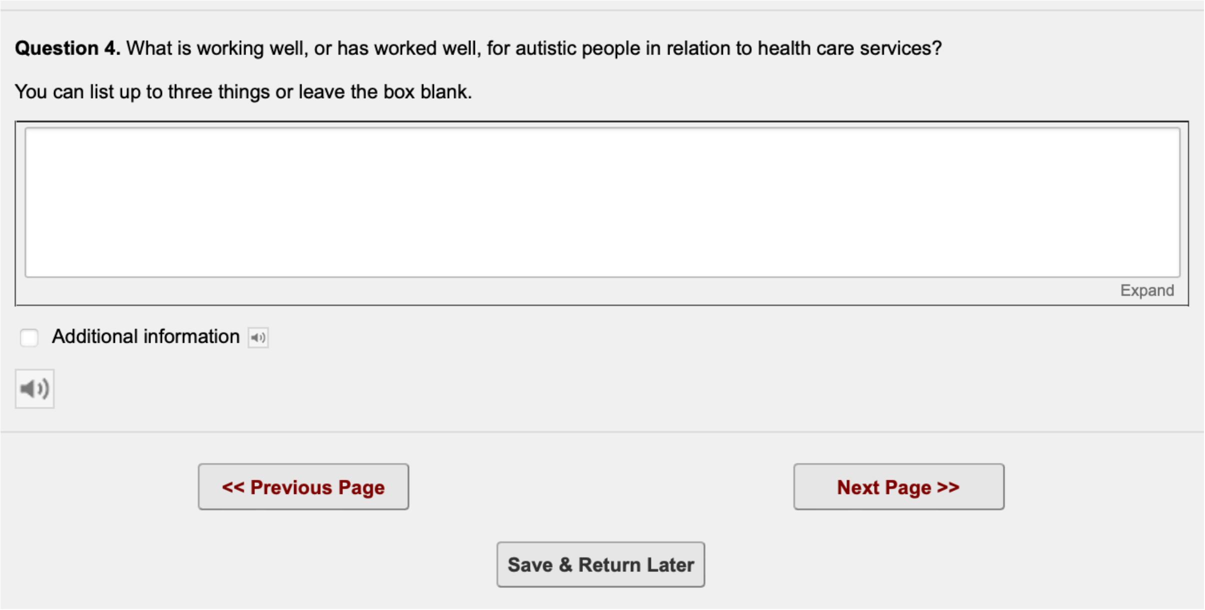
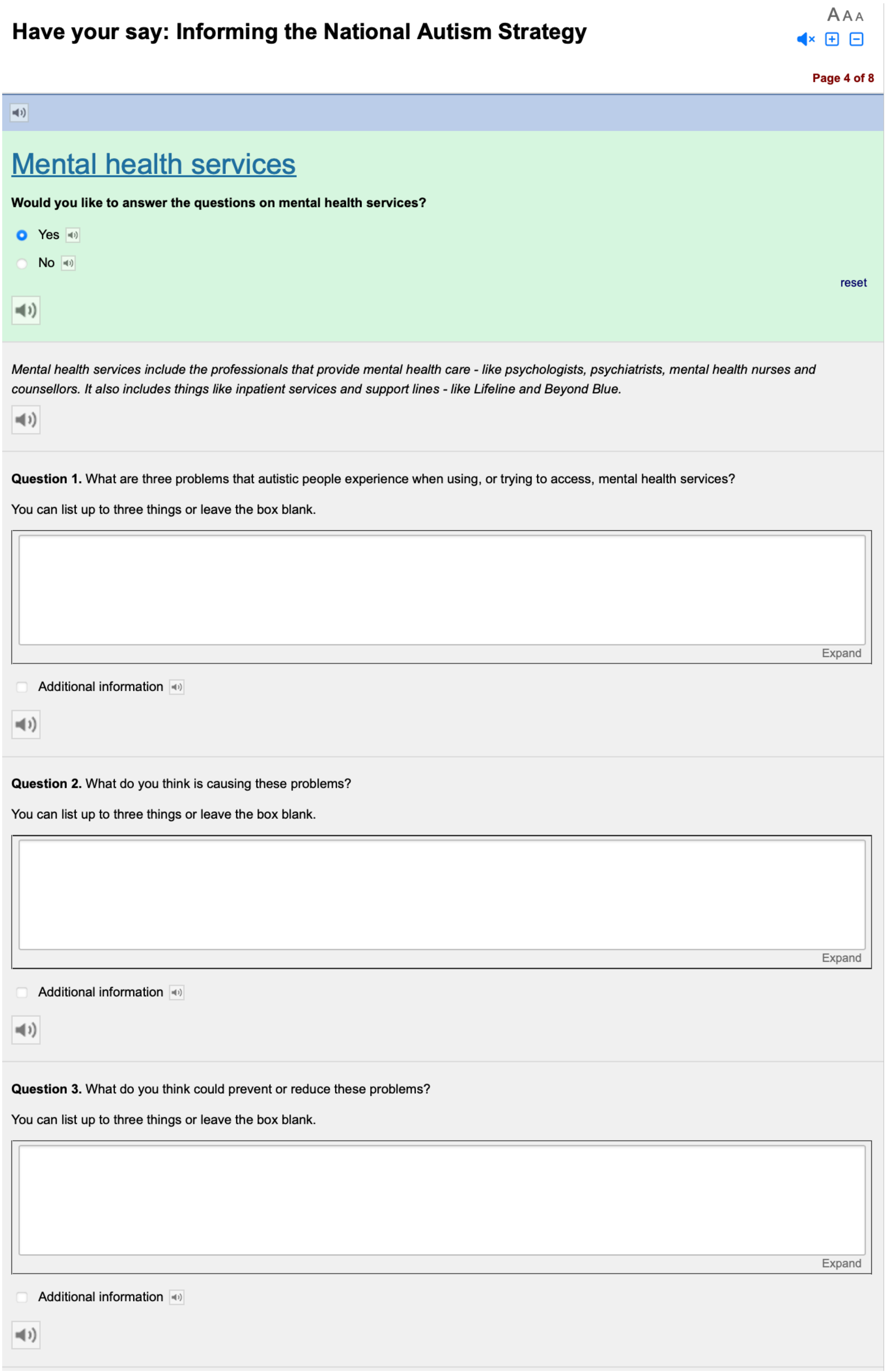


Question 4. What is working well, or has worked well, for autistic people in relation to health care services?

You can list up to three things or leave the box blank.



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Mental health services

Would you like to answer the questions on mental health services?

● Yes

○ No

Mental health services include the professionals that provide mental health care - like psychologists, psychiatrists, mental health nurses and counsellors. It also includes things like inpatient services and support lines - like Lifeline and Beyond Blue.

Question 1. What are three problems that autistic people experience when using, or trying to access, mental health services?

You can list up to three things or leave the box blank.

☐ Additional information

Question 2. What do you think is causing these problems?

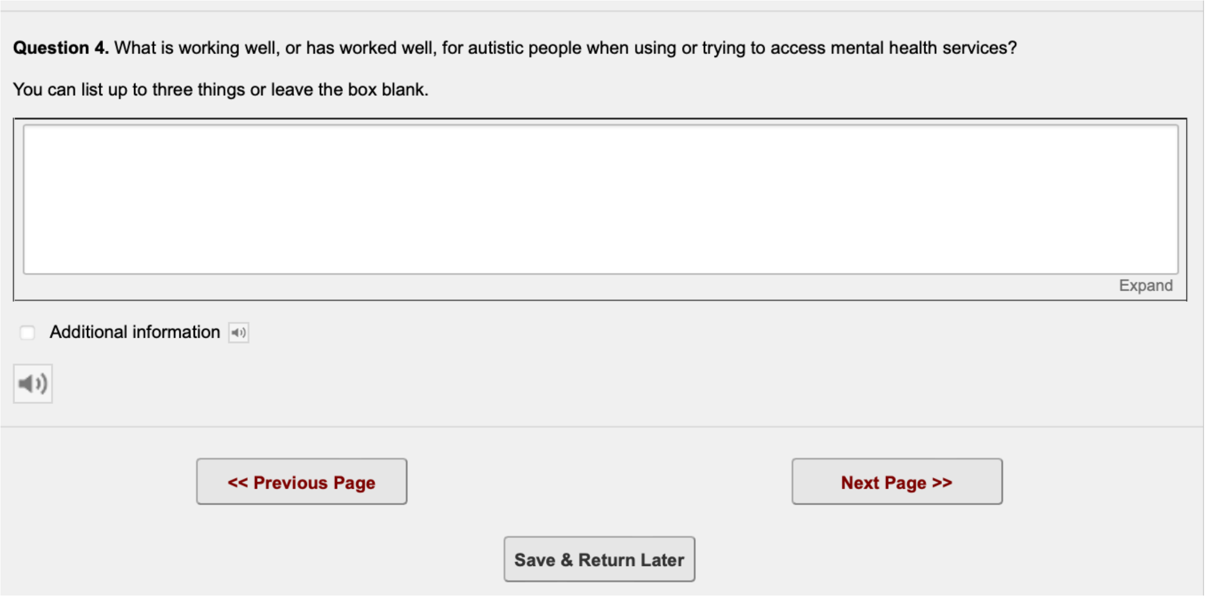
You can list up to three things or leave the box blank.

☐ Additional information

Question 3. What do you think could prevent or reduce these problems?

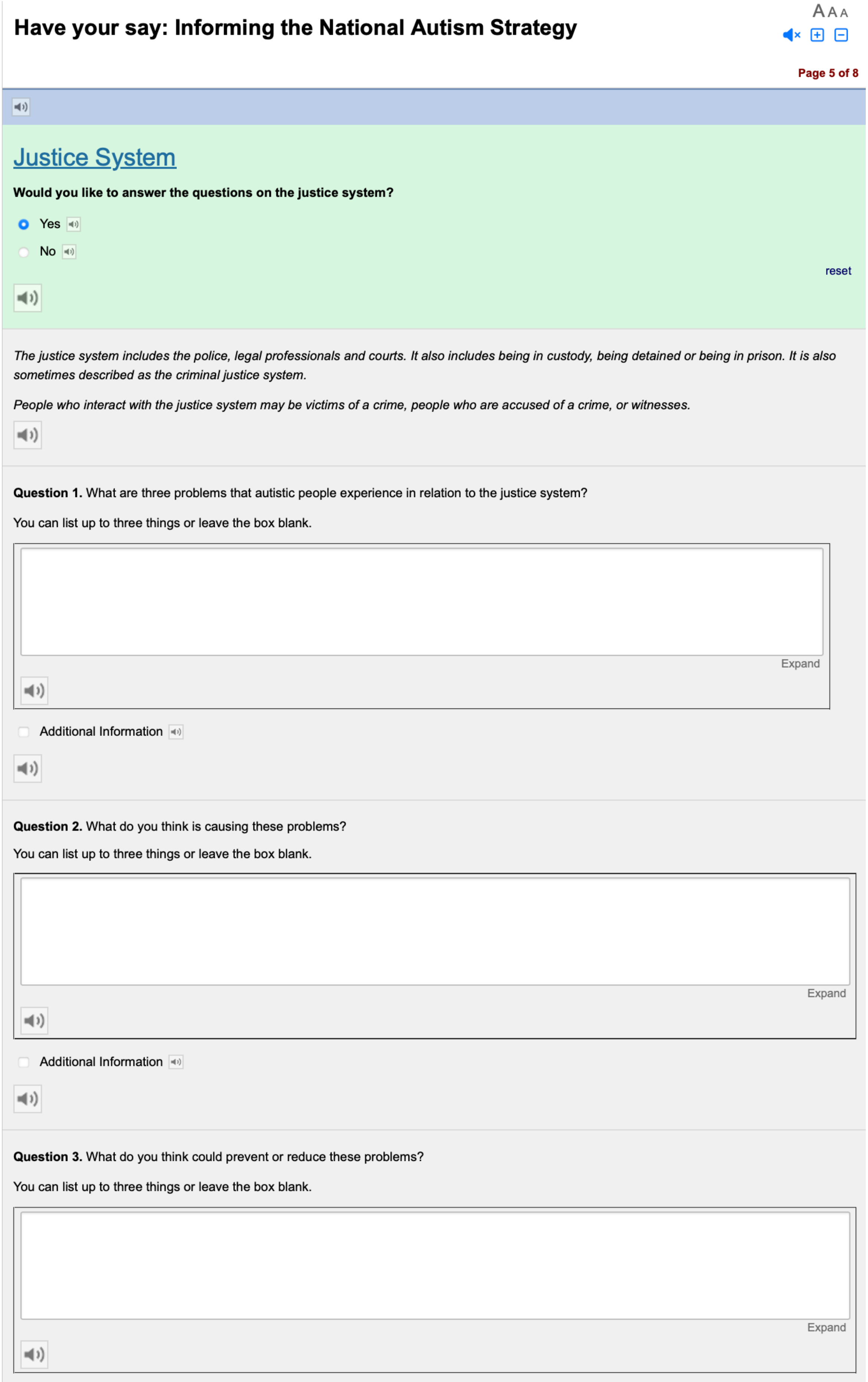
You can list up to three things or leave the box blank.

☐ Additional information



Question 4. What is working well, or has worked well, for autistic people when using or trying to access mental health services?

You can list up to three things or leave the box blank.



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Justice System

Would you like to answer the questions on the justice system?

● Yes

○ No

The justice system includes the police, legal professionals and courts. It also includes being in custody, being detained or being in prison. It is also sometimes described as the criminal justice system.

People who interact with the justice system may be victims of a crime, people who are accused of a crime, or witnesses.

Question 1. What are three problems that autistic people experience in relation to the justice system?

You can list up to three things or leave the box blank.

☐ Additional Information

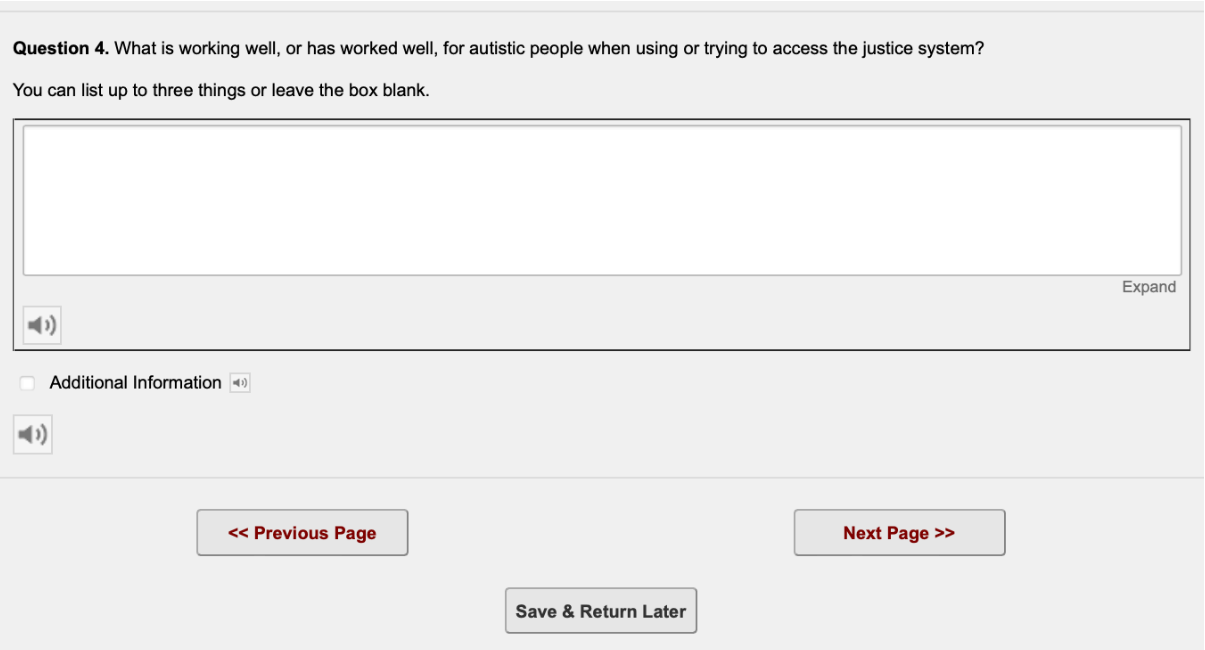
Question 2. What do you think is causing these problems?

You can list up to three things or leave the box blank.

☐ Additional Information

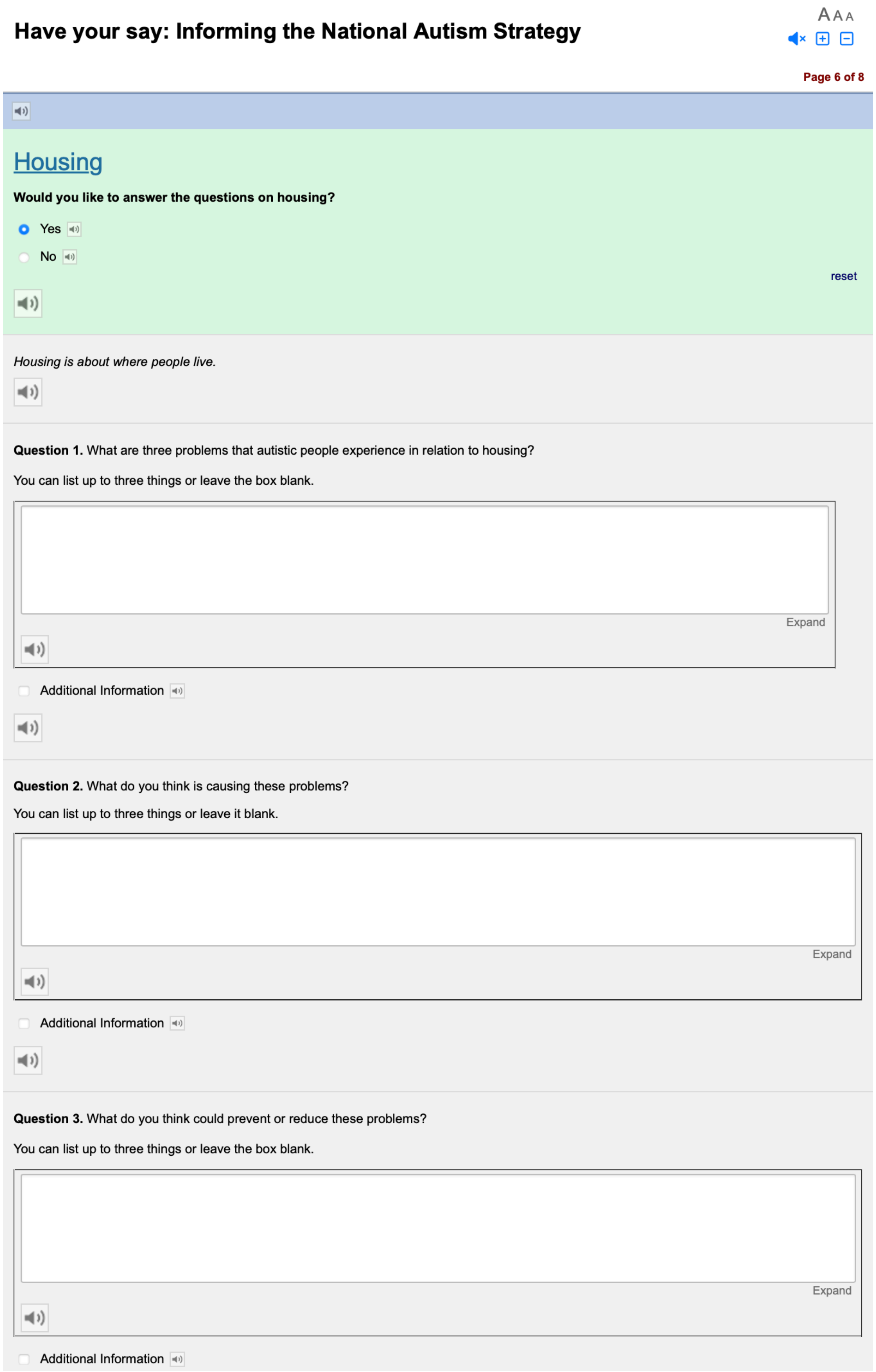
Question 3. What do you think could prevent or reduce these problems?

You can list up to three things or leave the box blank.



Question 4. What is working well, or has worked well, for autistic people when using or trying to access the justice system?

You can list up to three things or leave the box blank.



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Housing

Would you like to answer the questions on housing?

● Yes

○ No

Housing is about where people live.

Question 1. What are three problems that autistic people experience in relation to housing?

You can list up to three things or leave the box blank.

☐ Additional Information

Question 2. What do you think is causing these problems?

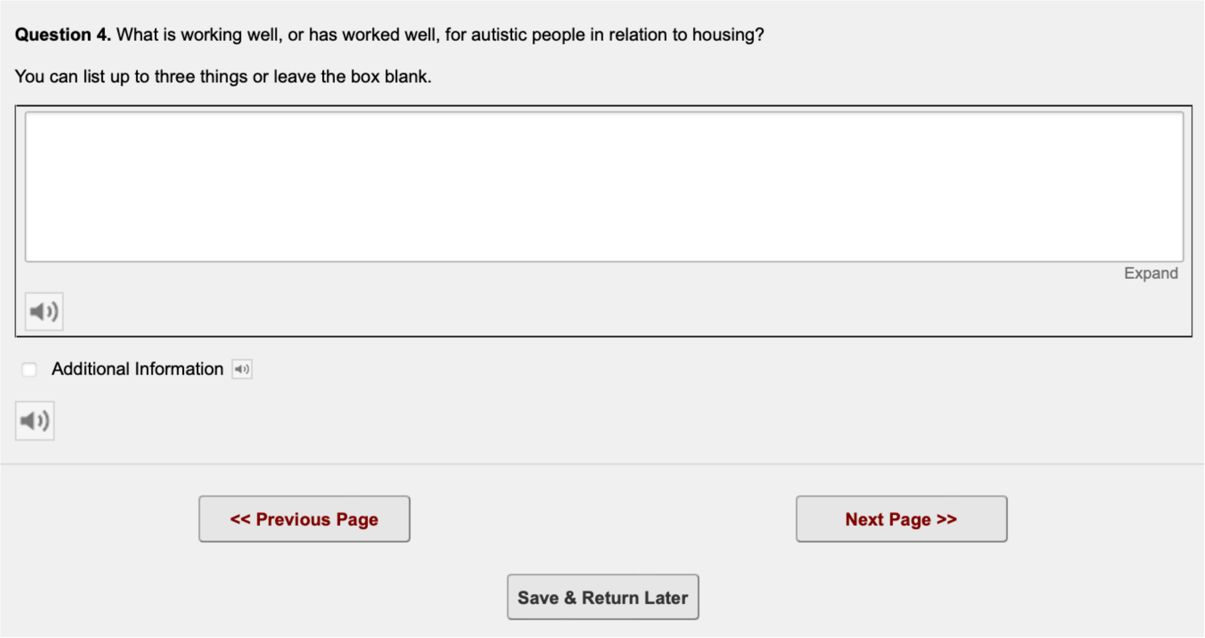
You can list up to three things or leave it blank.

☐ Additional Information

Question 3. What do you think could prevent or reduce these problems?

You can list up to three things or leave the box blank.

☐ Additional Information


Question 4. What is working well, or has worked well, for autistic people in relation to housing?

You can list up to three things or leave the box blank.

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Autism diagnostic services

Would you like to answer the questions on autism diagnostic services?

● Yes

○ No

We acknowledge that the term 'diagnosis' can be distressing for some autistic people. The term 'diagnosis' is used here it but it means the same as 'formal identification'.

Question 1. What are three problems that autistic people, and their families/carers, experience with autism diagnostic services?

You can list up to three things or leave the box blank.

☐ Additional Information

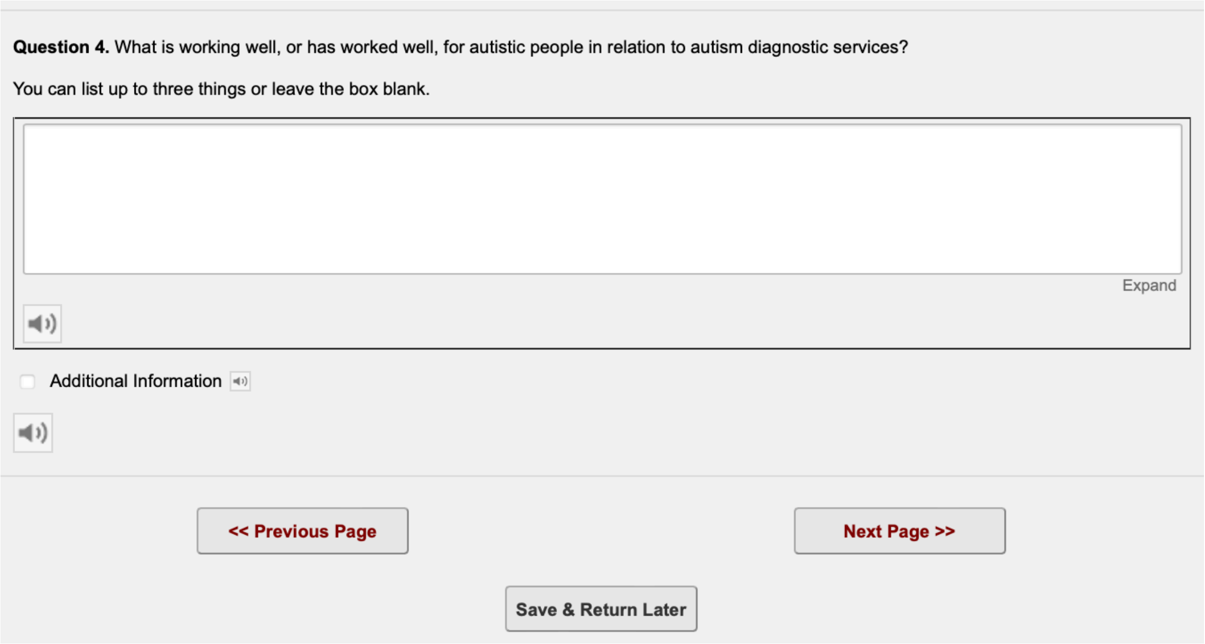
Question 2. What do you think is causing these problems?

You can list up to three things or leave it blank.

☐ Additional Information

Question 3. What do you think could prevent or reduce these problems?

You can list up to three things or leave the box blank.



Question 4. What is working well, or has worked well, for autistic people in relation to autism diagnostic services?

You can list up to three things or leave the box blank.

Have your say: Informing the National Autism Strategy

Early Intervention and Support Services

Would you like to answer the questions on early intervention and support services?

● Yes

○ No

Early interventions or supports are those offered in the early years of a child's life, generally up to 8 years old. Examples of early intervention and supports include language and behaviour skills, occupational therapists or support workers.

Question 1. What are three problems that autistic people, and their families/carers, experience when accessing, or trying to access, early intervention or support services?

You can list up to three things or leave the box blank.

☐ Additional Information

Question 2. What do you think is causing these problems?

You can list up to three things or leave it blank.

☐ Additional Information

Question 3. What do you think could prevent or reduce these problems?

You can list up to three things or leave the box blank.

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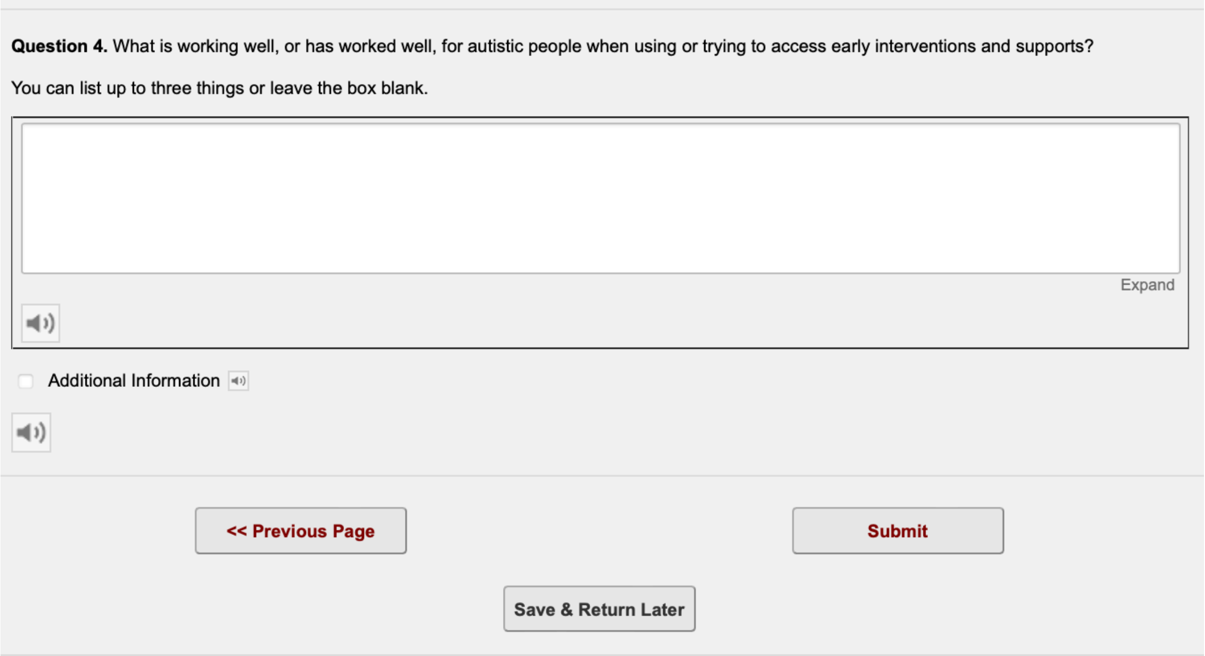


Question 4. What is working well, or has worked well, for autistic people when using or trying to access early interventions and supports?

You can list up to three things or leave the box blank.

Appendix C: Diagnosis

Appendix C-1: Content analysis categories

Question 1: What are three problems that autistic people experience when accessing, or trying to access, diagnosis services?

Rank	Problems experienced by autistic people and their family/carers in relation to diagnosis and sample quote from responses	% of all respondents who stated this issue
1	**Access to health professionals who are experts in diagnosing autism, especially in remote places** *"Professionals with the ability to diagnose autism for adults are few and far between. Unless you live in one of the capital cities, your chances of finding one are low."* (ID 479)	54%
2	**Long wait times for starting the diagnosis journey** (e.g., long waitlists, wait times being longer in public system, many services not accepting new clients) *"The waitlist for paediatrics is 3 years long and by the time the child is seen they are way past "early intervention"."* (ID 304)	52%
3	**High costs of pursuing an autism diagnosis especially when going through the private system** (e.g., those with financial problems miss out on diagnosis) *"High cost of diagnosis and diagnostic services for people who statistically generally have a lower earning capacity. Waiting lists for diagnostic services NDIS not covering the cost of diagnosis."* (ID 1000)	40%
4	**Health professionals with outdated knowledge of autism** (e.g., not recognising autism representations in females, adults, and those with less stereotypical behaviours, not recognising masking, ableist attitude towards autism, not recognising the vastness of the autism spectrum, trying to fit everyone into a box) *"Amongst professionals, a lack of awareness, training and true understanding of the complex variability of autistic expression and experience, especially for female and less 'stereotypical' cases ** even and especially amongst those whose job is the diagnosis and treatment of autism. The outcome is the denial and exclusion of truly autistic people who must struggle on without the assistance and accommodations they so dearly need that diagnosis would have opened up."* (ID 1512)	30%
5	**Gatekeepers' and educators (GPs, teachers) limited or outdated knowledge of autism**	9%

	(e.g., GPs lack of understanding of autism leading to no or delayed referrals, teachers not picking up the signs in a student, dismissing parents' concerns, not knowing how to inform, how or when one can pursue diagnosis) *"Dismissive and poorly educated GPs rejecting referrals for diagnosis because of their incorrect assumptions (i.e. autistic people can't make eye contact, girls aren't autistic, autistic people don't have the capacity to maintain relationships or careers, etc)."* (ID 246)	
6=	**Limited funding or financial support opportunities as pursuing a diagnosis is very expensive** (e.g., access to NDIS funding, medical rebates) *"Providers unwilling to help low-income people who feel they have autism get a diagnosis so that they can become a participant of NDIS and get the help they need. NDIS and other providers being unwilling to help people on low-income Centrelink payments with obtaining a diagnosis of autism."* (ID 153)	8%
6=	**Autism diagnosis manuals are deficit-based and are not co-designed with autistic individuals.** (e.g., outdated diagnosis manuals, focusing on stereotypical behaviours, extremely pathologising, not accounting for autistic strengths) *"The DSM5 is extremely pathologising and deficit based. It makes things difficult for clinicians using it if people are autistic but may not be demonstrating at that moment enough deficit even though in other situations or times they may. And it doesn't account for autistic strengths at all making it quite a traumatic experience to go through for many autistic people."* (ID 90)	7%
6=	**Health professionals not following the National Guideline for the Assessment and Diagnosis of Autism, resulting in miscommunication between the multidisciplinary team, misinforming families, not following a unanimous diagnosis pathway.** (e.g., inconsistent standards, differing opinions, the diagnosis pathway is confusing, assessments and the reports are vastly different) *"Maintaining diagnosis due to demands that lead to Autistic burnout living."* (ID 1330) *"Different diagnostics services will give different answers. Autistic people can have huge fluctuations in mood and it affects the diagnosis."* (ID 818)	6%
6=	**Lengthy diagnosis pathway** (e.g., long wait & see period, complexity due to presence of other co-occurring conditions) *"Takes years to get a formal diagnosis and lots of steps and different health professionals to go through."* (ID 1053)	6%
6=	**Misdiagnosis or over/under diagnosis of autism, with some health professionals pushing for an autism diagnosis.** (e.g., health professionals not spending enough time to accurately assess a person, some just diagnosis for NDIS funding, making it sound like autism) *"Many professionals do not understand the vastness of the spectrum. They are trying to get people with Autism to fit into the box for "Autism". They cannot see that everyone with Autism is different just like all neuro**typical persons have their differences. Professionals are too quick to diagnose any slight difference as Autism so that families can get access to NDIS Funding. This affects the people that really need the funding support."* (ID 1303)	6%
11=	**Health professionals blaming or dismissing family concerns** *"Families are consequently exposed to misdiagnosis, trauma, delay in early intervention. Family relationship breakdowns. Sibling trauma. Children seriously masking at school but*	5%

	*arriving home at the end of a school day and decompensating ** affecting family systems, self-esteem, physical and mental health. Families not believed as children are so adept at masking. Parents are often belittled by educators, teachers, school leadership that the behaviours are not exhibited at school therefore the problem is at home. No insight that home is often safe place."* (ID 1390)	
11=	**Families not informed about what autism is and what the diagnosis process involves** *"Parents of young children usually don't distinguish between autism diagnosticians and autism interventionists. Many diagnosticians relying upon indirect assessment of the child's learned skills and NOT conducting direct assessments (e.g., ADOS) that involve working with the child."* (ID 434)	5%

Question 2: What do you think is causing these problems and sample quote from responses?

Rank	Factors causing the problems experienced by autistic people and their family/carers in relation to diagnosis and sample quote from responses	% of all respondents who stated this issue
1=	**Issues with subsidisation or funding** (e.g., there is lack of funding such as NDIS support or medical rebates) *"Not sufficient fully funded services for parents to take children for assessment and diagnosis."* (ID 1227)	35%
1=	**Lack of trained specialists, services and resources for diagnosis** (e.g., hard to access health professionals, many tell families they have closed their books for the year) *"Not enough people able to diagnose."* (ID 207) *"Not enough providers with specialised skills."* (ID 558)	35%
3	**Health professionals' outdated understanding of Autism** (e.g., Health professionals' knowledge of autism is outdated and based on stereotypical symptoms such as eye contact, they are not familiar with female presentations.) *"Medical professionals having a pre-set belief of what an autistic person should present with for a diagnosis. e.g. pre-set belief of seeing features such as hand flapping, spinning or extreme sensory seeking behaviours as part of the diagnosis and not understanding how autism can present very differently along a spectrum."* (ID 995)	21%
4	**Outdated and deficit-based diagnostic manuals, resources and guidelines** (e.g., the diagnostic manuals have not been updated for a long time, guidelines and assessments are based on old-fashioned views of autism.) *"Many practitioners rely solely on assessment tools that have not been updated to reflect DSM-5 diagnostic criteria. They continue to hold diagnostically incorrect views, such as that you cannot be Autistic if you make eye contact, have empathy, or are social. This is causing significant harm through lack of correct identification for referral for assessment and misdiagnosis if a person presents for Autism assessment."* (ID 1330)	13%
5	**Diagnostic services struggle to meet the current demand** (e.g., not enough health professionals trained with diagnosis) *"Clearly there are not enough providers of government and private diagnostic services if it takes this long to be diagnosed."* (ID 312)	12%
6	**High cost involved for an autism diagnosis** (e.g., the expenses related to assessments and then writing the reports being high, those with lower socio-economic status especially adults cannot access diagnosis) *"They [families/autistic adults] have to pay for the diagnostic process themselves and all of the therapy until the funding is available. This funding also may not be enough."* (ID 170)	11%

7=	**Lack of trained autistic or autistic-informed health professionals** (e.g., inadequate training, not specialised in diagnosis, recognising more subtle presentations especially in females) *"There are less opportunities to become a psychologist. When there are less psychologists there are less specialising in autism, thus the ones available are overwhelmed with clients."* (ID 758)	8%
7=	**Community's lack of awareness about autism and its representations, especially in females and adults** (e.g., families or educators not recognising the signs, old fashioned perspectives, lack of acceptance and awareness in the society) *"General embarrassment in the community to talk about "being different" Fear that if something is identified, it will make it worse. General lack of knowledge concerning autism with people "who should know" ie child care, teachers, health professionals etc."* (ID 452)	8%
9	**Lack of Unified, standardised and collaborative approach** (e.g., inconsistencies in the system, poor communications within a multidisciplinary diagnosis team) *"A lack of unified approach to diagnose and support ASD. A lack of accountability and no regulatory oversight. Accountability needs to be genuine."* (ID 616)	6%
10=	**Lack of a government strategy, leading to bureaucracy and privatisation of the diagnosis process** (e.g., some just take advantage of the long waitlist in public to charge families more, elitism, bureaucracy in the system) *"The lack of action by the previous federal government in adequately funding and staffing the mental health system or making any attempt to address the ongoing problems and failings within the mental health and disability systems as clearly identified by thousands of people including experts in these areas and various enquires and parliamentary committee reviews."* (ID 1440)	5%
10=	**A need for training more health professionals with autism diagnosis** (e.g., Not enough health professional experts in diagnosis, train other professions to support diagnosis) *"Shortage of specialists and the time and cost associated with psychologist training and accreditation (I left a psychology degree due to the exorbitant amount I was going to have to pay for supervision)."* (ID 144)	5%
10=	**Unclear diagnosis process: Knowing when, how or why to get diagnosed** (e.g., the process in unclear, no idea when to start the diagnosis and who to contact) *"[Diagnostic services] do not advertise they are able to do autism diagnosis, you have to contact Autism organisations to find out who they are. The process is not made clear to carers or the autistic person. Once diagnosed, the provider does not have any contacts for further help in terms of services available and any government assistance." (ID 915)*	5%

10=	**Very long wait times to access specialists** (e.g., long queues to access health professionals, long waiting period in the public system) *“waiting times with public health can be 6-12 months which is an enormous long time for developing children.” (ID 1199)*	5%

Question 3: What do you think could prevent or reduce these problems?

Rank	Factors that could prevent or reduce the problems experienced by autistic people and their family/carers in relation to diagnosis services and sample quote from responses	% of all respondents who stated this issue
1	**Government funding, financial support or medical rebates** (e.g., Medicare subsidies for assessments, reimbursement through NDIS, rebate on assessments) *"More funding provided to diagnosis ASD for better access for vulnerable communities."* (ID 616)	53%
2	**Training health professionals with the nuances of autism** (e.g., symptoms in females and adults , masking) *"All healthcare professionals need to be trained about autism so that they can guide people appropriately."* (ID 18)	33%
3	**Increase the number of health professionals qualified to diagnose autism** (e.g., train more health professionals, other professions to deliver the assessments) *"Increase workforce numbers and capabilities linked to need and location."* (ID 141)	13%
4	**Enable more health professionals to be involved in diagnosis process** (e.g., having other professions such as general psychologists and OTs trained and accredited) *"Access to enough psychologists for assessments and therapies because only a small number of psychologists are endorsed "clinical" and by limiting assessments to only "endorsed" clinical or other psychologists, it is damaging for the general public... Amend the Autism Research recommendations to advise ALL psychologists can conduct autism assessments* (ID 555)	12%
5=	**Updating the diagnosis manuals/guidelines to be neurodiverse affirming and have criteria for adult diagnosis** (e.g., manuals that consider female representations, not deficit-based, consider diversity of symptoms) *"Fixing the DSM to add a new diagnosis for people who are diagnosed in adulthood."* (ID 40)	8%
5=	**Providing clear and uniform diagnosis process based on evidence-based practices, such as the National Guideline for the Assessment and Diagnosis of Autism** (e.g., guidelines for assessment tools, standardised practices, national and international guidelines) *"Follow the international standard of autism diagnosis"* (ID 426) *"Have clear and readily available guidelines."* (ID 47)	8%

5=	**Increase awareness of autism and its representations in community** (e.g., training parents and teacher to recognise the signs, autism awareness campaigns) *“A top-down culture change that is precipitated by open communication about differences. Changes to policies and procedures affected by the employee lifecycle. Opening up a channel for employees with neurodiversity (or disability in general) where there is forum for constant communication to senior levels of management. Awareness training for all would be- or already are- managers, regardless of whether their employees have disclosed disability.”* (ID 1415)	7%
8	**Tertiary education providers to train and support more students** (e.g., developing courses or diplomas that support experts for diagnosing autism such as in neurodiversity paediatrics) *“Fund tertiary education providers to train more students in neurodiversity paediatrics.”* (ID 129) *“Universities need to look at the skills gap in training psychologists qualified to diagnose.”* (ID 312)	6%
9	**Support students interested in professions in diagnosis** (e.g., financially support tertiary students, provide incentives) *“Include supervision as part of psychology degree programs. Don’t force psych graduates to have to fight to find a supervisor who then charges them half a year’s salary when they haven't even started earning a cent yet.”* (ID 144)	5%

Question 4: What is working well, or has worked well, in relation to autistic people accessing physical health services?

Rank	What is working well, or has worked well, in relation to autistic people and their family and family/carers accessing diagnosis and sample quote from responses	% of all respondents who stated this issue
1	**Knowledgeable and informed health professionals who are familiar with the nuances of autism** (e.g., representations in females, those with less stereotypical behaviours, autism is not about eye contact) *"Medical and allied health professionals who are well trained and up to date with best practice, evidence-based diagnostic criteria of autism."* (ID 822)	18%
2	**Nothing has worked, don't know** *"Nothing, this system is chaotic and there are so many stressed families waiting for answers."* (ID 1492)	15%
3	**Access to NDIS funding though very limited** (e.g., NDIS funding for some assessment sessions or health professional visits) *"Free government service which provided a quick pathway to accessing the NDIS while waiting for a formal diagnosis, noting this is only available to children seven years and under."* (ID 1162)	10%
4	**Some private service providers and limited organisations who are supportive of neurodiversity** (e.g., supporting costs, being neuro-affirming) *"Neurodiversity-affirming services are making a real difference to how the diagnostic process is experienced."* (ID 1192)	7%
5=	**When families or autistic people are already part of an established functioning multidisciplinary team** (e.g., already working with a multidisciplinary team who work collaboratively and communicate well) *"When the supportive network is good (the GP, counsellor, existing Psychologist), there is a natural flow into arranging diagnosis."* (ID 1040)	5%
5=	**Neurodivergent health professionals or those who are neurodiverse-affirming** (e.g., neurodivergent psychologist with lived experience, health professionals who acknowledge diversity and do not focus on deficits) *"There is a small but growing segment of neurodivergent professionals specifically serving the neurodivergent community, and a properly trained neurodivergent professional will in general provide much better outcomes than a neurotypical professional without lived experience."* (ID 246)	5%

Appendix C-2: Umbrella review search terms

Databases Searched

(title, abstract, and key words)

- PsychINFO
- Education Resources Information Centre (ERIC)
- Medline
- PubMed
- EMBASE
- CINAHL
- Cochrane Database of Systematic Reviews
- Scopus
- EBSCO Education Source
- Web of Science
- Epistemonikos

Search Terms

The following search terms were used to identify relevant articles

Autism	Review	Diagnosis
Autis* OR ASD* OR Asperger* OR pervasive developmental disorder* OR PDD* OR pervasive child development disorder* OR pervasive childhood developmental disorder* OR PCDD* OR disintegrative disorder*	systematic review* OR systematic literature review* OR evidence synthes* OR metaanaly* OR meta-regress*	diagnos*

Inclusion and exclusion criteria

Systematic reviews (SRs) were **included** in the umbrella review if they met all the following criteria:

1. The SR was a meta-analysis or a narrative synthesis (i.e., a SR without a meta analysis). A review was considered “systematic” if it: (1) included a clear statement of the purpose of the review; (2) described the search strategy (e.g., key search terms, multiple relevant databases, specification of search limits); (3) indicated the criteria used to select studies for inclusion; (4) presented all findings relevant to the main purpose of the SR; and (5) used a method of quality appraisal for each included study.

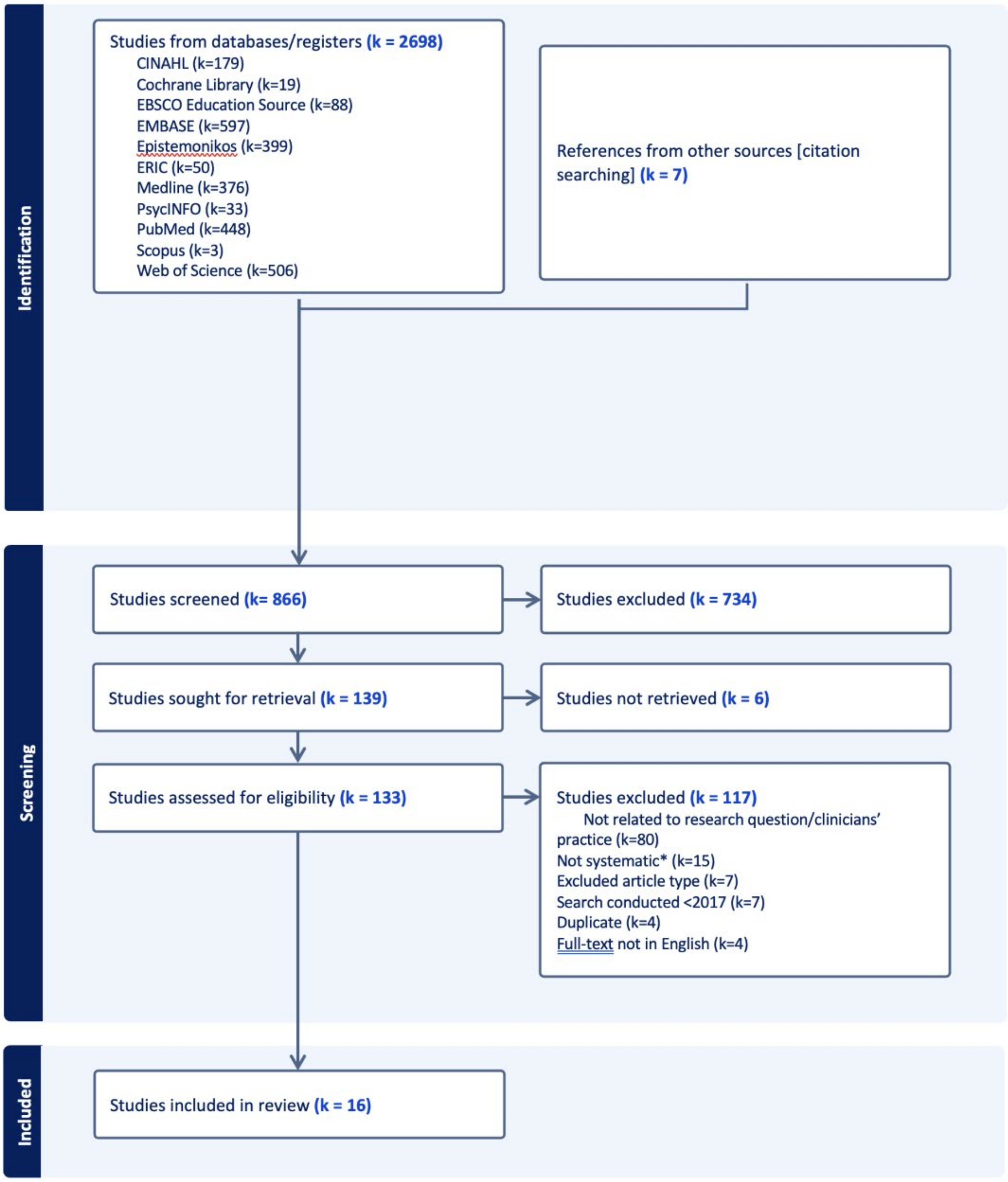
2. The SR reported on assessment and diagnosis for autism. SRs including diagnosis for other conditions in addition to autism could be included if results were reported separately for autistic individuals.
3. The SR focused, at least in part, on one of the following four areas:
    a. Recommendations to guide medical and allied health practitioners in assessing and diagnosing autism
    b. Clinical tools and processes that contribute to timely and accurate assessment and diagnosis for autism (e.g., consideration of diagnostic accuracy, location of assessment, single vs. multidisciplinary team, professional knowledge and experience etc.)
    c. Considerations regarding personal (e.g., gender, age) and environmental (e.g., residential location, financial resourcing) factors in assessment and diagnosis for autism
    d. The views and experiences of the autistic and autism communities regarding assessment and diagnosis for autism.
4. The results of the SR were relevant to one or more of the following questions related to guiding clinicians' practice in assessment and diagnosis:
    a. What guiding principles should be followed in the assessment and diagnosis of autism?
    b. In making a referral, conducting a functional, medical, and/or diagnostic assessment:
        i. When should this be considered?
        ii. Who should be involved?
        iii. In what settings should it occur?
        iv. What knowledge, skills, training, and support were required?
        v. What information should be collected?
        vi. How should information be collected
        vii. How should decisions be made?
        viii. What should be the outcomes?
        ix. How should information be shared?
    c. How should the quality and safety of assessment and diagnostic services be ensured?
5. The SR was published as a thesis, conference paper, scientific report, or peer-reviewed journal article.
6. The SR had a full-text copy available in English.
7. The final literature search was conducted in the last 6 years (2017-2022). If the search end date was not stated, then the SR was published in the last 6 years. There were no restrictions placed on the design of the studies included within each SR.

SRs were **excluded** if they met any of the following criteria:

1. The SR failed to meet one or more of the above inclusion criteria
2. The article was an umbrella review or “review of reviews”
3. The SR incorporated theoretical studies, text, and opinion as their primary source of evidence
4. The article was a protocol for a SR only
5. The SR focused exclusively on research related to understanding aspects of autism outside of the assessment and diagnostic process (e.g., aetiology, neuroimaging techniques, prevalence, developmental trajectories, factors impacting likelihood of autism including biomarkers, accuracy of screening tools and universal screening programs)
6. The SR had been superseded by an updated version of the same review (completed after full-text review of all SRs for all other eligibility criteria).

The SR was presented in a report, that has since been superseded by a scholarly publication (completed after full-text review of all SRs for all other eligibility criteria).

Appendix C-3: PRISMA diagram



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Appendix D: Early intervention and support

Appendix D-1: Content analysis categories

Question 1: What are three problems that autistic people, and their families/carers, experience when accessing, or trying to access, early intervention or support services?

Rank	Problems experienced by autistic people and their families/carers, in relation to early intervention and support services and sample quote from responses	% of all respondents who stated this issue
1	**Waitlists for accessing early intervention are too long** (e.g., the waitlists for allied health services/professionals are exceptionally long. Due to these long wait times diagnoses and interventions are delayed) *“The waitlist is over 12 months by this time the kids could have had really bad damaging experiences that will impact their life rather than the support they need when they need it.”* (ID 234)	34%
2	**Limited availability of early intervention services and trained staff** (e.g., there is a lack of trained staff that can work effectively with autistic individuals. Trained staff and interventions are especially difficult to access for people living outside the metro areas (e.g., in rural and remote areas). “*There is a distinct lack of intensive therapy services available. Access to early intervention should be a right for autistic children - not a privilege.”* (ID 84)	18%
3	**Finding information about the available services is a challenge** (e.g., it is difficult to find out what services are needed and what is available. It is difficult to know where to find the right information) “*Lack of knowledge of where these are in the community. How to access these services around work/family/life commitments.”* (ID 1035)	16%
4=	**Cost for accessing services and assessments is expensive** (e.g., early intervention and the costs associated with it (e.g., therapy, assessment) are expensive) *“Cost of services and time required to support individuals in a society which does not allow parents/carers to do this whilst maintaining their own self-care makes it extremely difficult. .”* (ID 1222)	14%
4=	**Difficulty accessing support services** (e.g., not knowing how to find services, what is available, or how to access support services; the system can be confusing and difficult to navigate; not being able to get to appointments) “*The system is very confusing to navigate and often requires a high level of self-advocacy skills.”* (ID 995)	14%

6=	**General lack of understanding autism** (e.g., lack of understanding autism in girls/women; masking is commonly misunderstood) *“Some support services promote masking, teaching autistic children they are 'broken' and needing to change to be accepted. My 10-year-old autistic child was brought to tears in multiple OT appointments because they kept trying to force her to recognise emotions that did not make sense to her.”* (ID 976)	12%
6=	**Having choice of therapy options that are based on the individuals’ needs** (e.g., there need to be different types of therapy that cater to the individuals’ and the family’s needs such as individualised, at home, sensory aware, family centred, alternative therapies, strength based) *“Knowing which support to prioritise and what the cost/benefit is of different therapies. Knowing if you're avoiding ableist therapies that seek to change autistic people.”* (ID 376)	12%
8=	**Not accessing early intervention because autism diagnosis has not been confirmed** (e.g., if the child has not yet been diagnosed it is very difficult to access early intervention services) *“But from experience, paed[diatrician]s and psych[ologist]s are unwilling to provide official diagnoses until children reach school-age, and by then the window of opportunity for early intervention has passed.”* (ID 162)	10%
8=	**Lack of support for families** (e.g., there is not enough evidence-based information for families. The support available is not tailored enough and often does not focus on the family (e.g., often overlooks siblings) *“Not enough support for the family of the autistic person - i.e. little information, no pathways to finding information”* (ID 242)	10%
10	**Difficult to find or lack of quality good therapists/therapy/staff** (e.g., it is a challenge to find good quality services and therapists; difficult to know how to find the right people; difficult to know whether the therapy is good) *“Providers who do not work in best practice approach e.g. not working in natural settings, limited focus on parent engagement or capacity building, emphasis on weekly sessions being only option offered or only chance of 'success' in meeting therapy goals, seeing change etc.”* (ID 1070)	9%
11	**Lack of, and finding, neuro-affirming therapists, therapy or interventions** *“All of these interventions are prefaced on the idea that autistic people have a deficit rather than there being a difference between autistic and non-autistic people.”* (ID 446) *“The idea of interventions that teach us not to be autistic. We need support. We should not be trained at an early age to always comply, and to deny our own needs and experience of the world”* (ID 955)	8%
12=	**Criticism of NDIS staff – knowledge, understanding, training, administration processes etc**	7%

	"The idea that people should perform early intervention so that they don't need support later in life, and not because it holds the best chance of improved life outcomes from the person with a disability." (ID 940)	
12=	**Criticism of NDIS funding** *"Stop the madness of pressuring parents to get a diagnosis before the child turns 7y… so, increase the capacity of NDIS funding to make the diagnosis within the NDIS system so they are not waiting forever for a diagnosis"* (ID 1124)	7%
13	**Accessibility - early intervention and support services** *"Access to evidence-based therapy due to lack of providers specialising is autism. Lack of funding for the level of therapy our younger children need to reduce the severity of their autism symptoms. They need more than a hour a week! Lack of implementation of early behaviour interventions and easy access to this."* (ID 579)	6%
14=	**Difficulty accessing and limited access to funding** *"Timeliness of getting access, of you don't have much money or lack experience navigating systems and advocating for your child it's really hard."* (ID 444)	5%
14=	**Limitations on how NDIS funds can be used** *"Difficulty in accessing funding for parent training and Improved Relationship funding for this age group"* (ID 822)	5%
14=	**Difficulty navigating or accessing NDIS, regular reviews and other systems** *"The length of time to get a diagnosis so missing the early intervention window and not knowing what supports are out there. Lack of available supports, including experienced therapists, particularly in regional or rural locations. Not understanding the NDIS and the lack of non-NDIS funded supports."* (ID 994)	5%
14=	**Therapy is stressful or traumatic (for child/ family)** *"Reliance on behaviourist interventions that are traumatic for autistic people - A lack of neuro-affirming interventions"* (ID 246)	5%
14=	**Acceptance /denial of diagnosis and social stigma** *"Diagnosis can sometimes mean discrimination in communities where there is limited knowledge of autism."* (ID 690)	5%

Question 2: What do you think is causing these problems?

Rank	Factors causing the problems experienced by autistic people and their families/carers, in relation to early intervention and support services, and sample quote from responses	% of all respondents who stated this issue
1	**Lack of specialist services and trained professionals who can provide early intervention and supports** (e.g., lack of trained staff to deliver neuro-affirming services. Lack of training for staff) *"Practitioners using non-supported practices"* (ID 170) *"Shortage of early intervention professionals (e.g., speech pathologists, occupational therapists)."* (ID 319)	22%
2	**Limited funding and financial support opportunities** (e.g., not enough funding for appropriate (early intervention) services and support for carers and the individual; lack of federal and state funding) *"Funding, and an unwillingness to support these services."* (ID 1394)	11%
3	**Untrained NDIS staff who have limited understanding of the needs of autistic people** (e.g., NDIS workers and planners are often not trained in autism and therefore do not understand the needs of the individual and their family) *"Lack of willingness or understanding from the NDIS around how support workers can assist in capacity building children."* (ID 266) *"NDIS planners are not equipped to understand or interpret allied health reports and recommendations accurately."* (ID 998)	10%
4=	**Restrictions posed by NDIS on the services families can access and their costs** (e.g., NDIS limits on therapy funding means that not all needs are addressed) *"Limited NDIS funding that often does not match the supports required."* (ID 317)	9%
4=	**Gatekeepers and educators' lack of understanding of autism and services they can access** (e.g., more education about autism is needed for educators, gatekeepers, and health professionals) *"Teachers are afraid to use the word Autism when approaching parents, teachers are not able to diagnose & do not receive training in what to look out for. They often think children are just naughty or disruptive."* (ID 149)	9%
6=	**The early intervention services are expensive** (e.g., services are overpriced, and everyone charges the maximum amount; not everyone can afford the services) *"Poverty - families with autistic children tend to be financially challenged."* (ID 935)	7%

6=	**Community's lack of awareness and understanding of autism** (e.g., there is a lack of education in the community which leads to a lack of awareness and understanding of autism in the community) *"Lack of understanding and knowledge about the differences in autistic people"* (ID 976) "*Parents who want someone to 'fix' their child and not understand they can learn strategies to support their child's development and ability to participate in the community."* (ID 753)	7%
8=	**Lack of support and education for families** (e.g., not enough supports and tools for families to support their children and themselves) *"Without supporting the family, the neurodivergent person's world collapses. Families are often undiagnosed neurodivergents themselves and are not receiving support. Siblings are often also affected and do not get support."* (ID 180)	6%
8=	**Access to information or resources available to families** (e.g., families are not sure where to find the right information; lack of centralised information, which can make it difficult and overwhelming for parents to access information) *"I think parent education (if diagnosing for a child) is key and there are many organisations that can facilitate this, some of which are autistic led (and for myself and my son, the most worthwhile and effective)."* (ID 190)	6%
8=	**Access to early intervention service and support** (e.g., there are several barriers to access early intervention services and support, such as funding, and time to access the services; not enough allied health services to meet the high early intervention service demand) *"For those with not complex needs, a lack of short term and generalized early intervention supports within the community or at mainstream day-care and prep."* (ID 994)	8%
9=	**Lack of coordination between government agencies** *"There is a barrier between the education department and the NDIS, we need support in the middle. Our kids spend a considerable amount of time at school and the support needs to cover both. Early intervention is absolutely vital in both areas."* (ID 206)	5%
9=	**Complicated pathways to find and access help and support** *"I think parent education (if diagnosing for a child) is key and there are many organisations that can facilitate this, some of which are autistic led (and for myself and my son, the most worthwhile and effective). In saying that, accessing NDIS funding is a nightmare, and if it weren't for the networks of people I had researched about and talked to helping us (which cost money), then I would most certainly not been able to attain funding and support my child."* (ID 190)	5%

Question 3: What do you think could prevent or reduce these problems?

Rank	Factors that could prevent or reduce the problems experienced by autistic people and their families/carers, in relation to early intervention and support services, and sample quote from responses	% of all respondents who stated this issue
1	**More funding and financial support** (e.g., increased and better funding is needed to support families to access appropriate services; more government funding and funding for research is needed) *"More funding to encourage more access and more quality supports in service delivery."* (ID 616)	22%
2	**Access to more early intervention providers and programs** (e.g., increase availability of early intervention providers, especially in regional areas) *"Work with professional registration bodies to identify strategies to increase capacity to provide early intervention services."* (ID 317)	17%
3	**Access to more autistic or neuro-affirming health professionals** (e.g., more training and education for health professionals on how to provide neuro-affirming services) *"Neuro-affirming OT support that doesn't aim to change or fix autistic children. Instead provide them with the tools to navigate the neurotypical world."* (ID 976)	16%
4	**Government investment in training more health professionals for delivering early intervention and supports** (e.g., more government investment to support professional development, training, and university courses to train more health professionals) *"Funding free courses for [service provider's name] to deliver training to schools and childcare."* (ID 408)	15%
5	**Provide individualised therapy options for families** (e.g., more therapy option would help to address the individual's and family needs) *"An understanding that every child is different and has different needs."* (ID 1021) *"Letting the autistic person lead their own learning if possible - help them with what they decide they want to work on and learn about."* (ID 1320)	13%
6=	**More support for families** (e.g., more education for families (parents, children, and their siblings) will help them to access the services and systems) *"Better support for families with autistic children. I don't think the bonus payment for carers has gone up in a decade. What would buy supports or novel interventions a decade ago doesn't go that far these days."* (935)	12%
6=	**Access to early intervention and support without a confirmed diagnosis** (e.g., access to early intervention and supports provided during or prior to assessment to provide early interventions and supports to all autistic individuals) *" Allow access to early intervention services during the assessment phase and not only after the diagnosis is formalised.!"* (ID 426)	12%

8	**Need more support in schools or early childhood education settings** (e.g., more staff) *"Increased early intervention facilities through Education."* (ID 666)	10%
9=	**Access to NDIS funding** (e.g., improved policies and procedures supporting access to NDIS funding; more funding for early intervention services and supports) *"More funding for permanent and for visiting specialists and allied health outside the major cities."* (ID 992)	9%
9=	**Improve understanding and awareness around autism** (e.g., more training and education for professionals and the community) *"Train professionals to value being autistic and not to presume autistic people want to be neurotypical or want to learn how to cope with unreasonable neurotypical demands and environments."* (ID 151)	9%
10	**Education in the community** *"GPs, paediatricians, SLPs, Child Psychologists, OTs and physios need education and reminders to provide concerned parents with information on the availability of early intervention services and in addition: infographic posters in waiting rooms, adverts in Facebook reels, advertisements, letter-box drops, headers on paediatric notes pages"* (ID 844)	8%
11=	**Information, resources and education for parents/ family** *"Increased access to support work for families of children on the spectrum. Automatically building into NDIS plans funding for school holiday therapy sessions."* (ID 266) *"Increased early intervention facilities through Education Queensland Information pack developed to support families during after diagnosis phase"* (ID 666)	7%
11=	**Need more parent involvement** *"linking funding to parental involvement in therapy"* (ID 618)	7%
11=	**Listen to autistic voices, insights and experience** *"Listen to autistic people's insight and experience. Bring them into the systems to inform them."* (ID 24)	7%
14=	**NDIS - improve knowledge, understanding, training, administration processes etc** *"Behaviourism - audit and overhaul training and therapy systems to weed out compliance based systems and replace them with support and knowledge based person centred systems.*" (ID 1512)	6%
14=	**Navigating the NDIS, regular reviews and other systems** "*Doctors, maternal health care nurses, kindergartens have How to apply for NDIS factsheets. *I had done 4 different parent designed courses by Amaze and Association of Children with Disabilities, these were free and readily available once found them.*" (ID 429)	6%
14=	**Government policies and procedures**	6%

	"A significant impartial review of the policies and procedures being adopted by NDIA when determining funding for children with ASD" (ID 434)	
14=	**Accessibility – NDIS and services better access to supports** *"Increase public access to providers through a scheme or medicare. improve awareness of services - not many know exactly what an OT can do, or an exercise physiologist etc. HCWA [Helping Children with Autism] Program is not well advertised"* (ID 427)	6%
18=	**Update evidence/ (diagnostic) services** "*Ensure psychology organisations (PBA, Universities, professional associations) recognise the limitations of clinical masters programs. Have NDIS recognise suitably experienced generally-registered psychologists (not just clinical psychs) as being able to provide definitive diagnosis, without paediatrician opinion."* (ID 354)	5%
18=	**Need more professionals who work together (trans-disciplinary model)** "*Making Key Worker salary more attractive. They are paid a low amount while the company is getting $193.99 per hour from NDIS. These makes Key Workers leave to start their own business as an OT, Speech or Early childhood specialist and then the children are not receiving trans disciplinary therapy and support."* (ID 753)	5%
18=	**Acceptance/ denial of diagnosis and social stigma** *"Education, more understanding and compassion"* (ID 219) *"Decreasing stigma around diagnosis"* (ID 284)	5%

Question 4: What is working well, or has worked well, in relation to autistic people when using or trying to access early interventions?

Rank	What is working well, or has worked well, in relation to autistic people and their families/carers in relation to early intervention and support services and sample quote from responses	% of all respondents who stated this issue
1	**Financial support and funding through NDIS** (e.g., where the funding is appropriate/sufficient; access to range of supports.) *"NDIS funding is good, so long as it is flexible and can be used for a variety of therapies."* (ID 90)	21%
2	**Having access to early intervention services and support services as early as possible** (e.g., once the access to early intervention services is granted, the services work well, especially if accessed early on) *"Early Intervention/access to specialised setting to set them up for success before accessing mainstream schools."* (ID 284) *"Once access is finally granted and funded it works amazingly well for the patient."* (ID 1293)	20%
3	**Enabling families to choose from available therapy options** (e.g., specialised services, therapy in real life scenarios, family and person-centred therapy) *"For people who are self and planned managed, many are choosing to redirect funds from other therapies towards ensuring access to music therapy. This design feature in the NDIS is thus enabling choice and control for people with disability, as it should."* (ID 916)	14%
4	**Evidence-based practice and using evidence from research** (e.g., more autistic co-designed research; research that clarifies misinformation; research on the effectiveness of early intervention) *"Research unequivocally demonstrating that early intervention not only facilitates notable developmental progress for autistic children, but also yields impressive returns on investment. The research substantiates the life-changing impact early intervention services can have on autistic children."* (ID 1556)	13%
5=	**Choice of intervention through NDIS support** (e.g., families being able to choose the type of intervention like music, art) *"Access to NDIS and therapy services. Early Intervention/access to specialised setting to set them up for success before accessing mainstream schools."* (ID 284)	9%
5=	**Utilising the expertise of allied health professionals** (e.g., health professionals with expertise in autism and who are neurodivergent and can deliver neurodiversity affirming services) *"The thorough use of speech therapists, paediatricians and psychologists to give a thorough assessment so the proper supports can be accessed."* (ID 596)	9%

5=	**Individualised therapy choices** (e.g., therapy that is individualised, regular, consistent, and family and person-centred) *"Allied health professionals who understand the need to travel to a child's preferred environment, to increase the level of engagement and so provide value for money for the therapy and better outcomes for the child."* (ID 831)	9%
5=	**Choice of early intervention and supports available to all families** (e.g., having different options of early interventions available, such as Telehealth) *"Early intervention flexibility, when a parent can receive NDIS support to access private providers."* (ID 1011)	9%
5=	**Support families to navigate the system and self-advocate** (e.g., being given opportunities to communicate and share experiences with other parents; support groups, carer support services, early childhood development programs and respite care work well for families) *"We used [service provider's name] early intervention partner. I found them very good. They didn't find the services for us, but they set us on the right track."* (ID 1251)	9%
5=	**Support for parents, siblings, family, including respite and specialist playgroups** *"Carer support services and respite care makes more difference than weekly individual therapy (respite is rarely available for young children under age 7 and it should be for some families)"* (ID 1055)	9%
10=	**Support from parents - advocacy, persistence** *"Parents confidence in getting the diagnosis and advocating for their kids."* (ID 255) *"Parents advocating for services and support"* (ID 590)	7%
10=	**Support from allied (multidisciplinary) health teams** *"Being able to have different therapists at the same clinic (e.g. OT and Speech Pathologist)" (ID 489)*	7%
12=	**Autistic informed information** *"Autism Connect a service run by Amaze that employs and is informed by Autistic people is an excellent organisation with clearly accessible and relevant information for everyone about autism"* (ID 287)	6%
12=	**Support groups, other parents, peer support** *"We attended a free Early Years playgroup with the Autism Association for a while before we got NDIS and this was free, and so informative, and well-worth the 40 minute drive there and back."* (ID 1251)	6%
13=	**Early intervention services that have an impact on the child's development** (e.g., early intervention services can provide an autistic child and their family with the right tools, knowledge, and support; early education, autism services, services providing autism information sessions, and general support services are reported to work well)	5%

	"[A service's name] a service run by [organisation's name] that employs and is informed by Autistic people is an excellent organisation with clearly accessible and relevant information for everyone about autism (everything you want to know)." (ID 287)	
13=	**Therapy early intervention in day care, group sessions** *"Children do need active engagement, but it needs to be based on following the child's lead, not rewarding a child for doing a compliance based activity. Something like the SCERTS model by Prizant and co is great for planning what a child needs in terms of normal developmental milestones, focusing on joint attention, not eye contact and spontaneous self initiated communication, not simply a rote response."* (ID 416)	5%
13=	**Understanding and supportive schools and teachers** *"Preschool teachers who can identified needs and referral pathways to access early interventions"* (ID 141)	5%
13=	**Understanding - Other people who understand, general awareness** *"...understands and sees the positive rather than the negative of being on the spectrum" (ID 168)*	5%
13=	**Nothing/ not much/ don't know** *"People are not happy with funding now. Too many rejections, waiting lists, lots of documents to be filled in. No clear communication, explanations"* (ID 573)	5%

Appendix D-2: Umbrella review search terms

Databases Searched

(title, abstract, and key words)

- CINAHL
- Cochrane Database of Systematic Reviews
- EBSCO Education Source
- EMBASE
- Education Resources Information Centre (ERIC)
- Epistemonikos
- Medline
- PsycINFO
- PubMed
- Scopus

Grey literature search:

- Google advanced search (limited to first 100 results per search)
- PROSPERO
- Abstracts submitted to International Society for Autism Research (INSAR) conferences, and identification of corresponding full text publications.

Search Terms

The following search terms were used to identify relevant articles

Autism	Review	Intervention
Autis* OR ASD* OR Asperger* OR “pervasive developmental disorder*” OR PDD* OR “pervasive child development disorder*” OR “pervasive childhood developmental disorder*” OR PCDD* OR “disintegrative disorder*”	“systematic review*” OR “systematic literature review*” OR “evidence synthes*” OR “meta-analy*” OR “meta-regression*”	intervention* OR therap* OR treat* OR teach* OR program* OR package*

Inclusion and exclusion criteria

Systematic reviews were included in the umbrella review if they met the following inclusion criteria:

1. The review was a systematic review, with or without meta-analysis. A review will be considered “systematic” if it: (1) includes a clear statement of the purpose of the review; (2) describes the search strategy (i.e., key search terms, multiple relevant databases, specification of search limits); (3) indicates the criteria used to select studies for inclusion; (4) presents all findings relevant to the main purpose of the review, including those that did not favour the intervention; and (5) uses a method of quality appraisal for each included study

2. The systematic review reports on at least one non-pharmacological intervention that targets the acquisition of developmental or educational skills
3. The systematic review includes at least one clinical trial (RCTs), quasi-RCT, and/or controlled clinical trial. Systematic reviews that include studies with other designs will be included only if they also feature at least one randomised controlled trial (RCTs), quasi-RCT, and/or controlled clinical trial
4. The systematic review reports summarised, quantitative data on the impact of the intervention on one or more of the main outcomes of interest (described below)
5. The systematic review is published in a peer-reviewed journal or published as a publicly available scientific report
6. The systematic review has full-text copies available in the English language
7. Systematic reviews that report on interventions that were trialled in children on the autism spectrum (0-12 years of age). Systematic reviews that include children described as increased likelihood or suspected of autism will be included only if the review also included children on the autism spectrum. Systematic reviews that specify in the aims and/or search criteria that studies including children with developmental conditions other than autism (e.g., Down syndrome, global developmental delay) were specifically targeted, will only be included if outcomes were reported separately for children on the autism spectrum. Data will also be extracted from reviews which report on caregiver outcomes as described in the outcomes section
8. Priority for inclusion will be given to systematic reviews that are either limited to, or report outcomes separately for younger children (within the age range of 0-12 years). Where there are no systematic reviews identified for a specific intervention that meets this criterion, we will include systematic reviews that report outcomes for children both within and beyond the 0-12 age range.

Systematic reviews were **excluded** from the umbrella review if they met the following inclusion criteria:

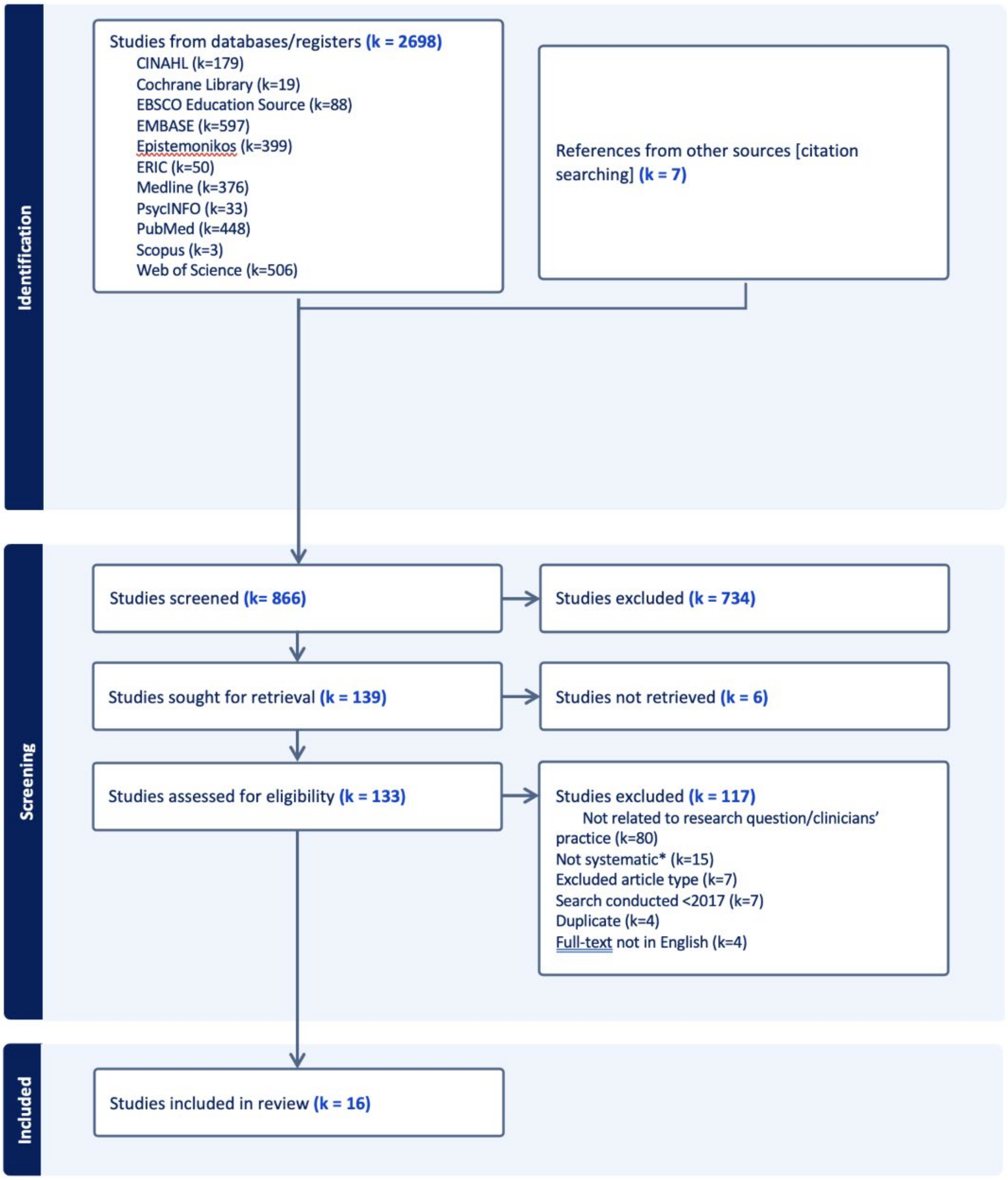
1. Systematic reviews that do not meet the criteria to be considered “systematic”
2. Umbrella reviews, rapid reviews, or “reviews of reviews”

Systematic reviews that did not include at least one RCTs, quasi-RCT, and/or controlled trial.

3. Systematic reviews that did not report on at least one non-pharmacological intervention that targets the acquisition of developmental or educational skills
4. Systematic reviews focussing solely on dietary, sleep, exercise, chiropractic, massage, acupuncture, reflexology, kinesiology, shock therapy, neurofeedback, transcranial magnetic stimulation, or hyperbaric oxygen therapy interventions. While non-pharmacological, these interventions are beyond the scope of the review

5. Systematic reviews focusing solely on techniques (defined as one specific strategy) rather than an intervention (i.e., a collection of techniques)
6. Systematic reviews that did not report summarised outcomes of interest relevant to the current umbrella review
7. Systematic reviews that incorporate theoretical studies, text, and opinion as their primary source of evidence
8. Theses, conference papers, newsletters
9. Systematic reviews where full-texts are not available in English
10. Systematic reviews that report on interventions with children with other developmental conditions that are not autism, or where outcomes for children on the autism spectrum specifically cannot be extracted and those that only include children described as increased likelihood or suspected of autism
11. Systematic reviews that do not involve children ≤12 years of age and/or include individuals over 18 without a separate analysis of younger children. If a systematic review for a specific intervention is identified that reports outcome separately for children 0-12 years of age, then we will exclude systematic reviews of the same intervention that involved children over 12 years of age without a separate analysis of younger children.

Appendix D-3: PRISMA diagram



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Appendix E: Primary and secondary education

Appendix E-1: Content analysis categories

Question 1: What are three problems that autistic people experience with education?

Rank	Problems experienced by autistic people in relation to education and sample quotes from responses	% of all respondents who stated this issue
1	**A lack of teacher awareness, knowledge, and/or experience in autism (and broader neurodiversity), its heterogeneity, and associated needs** (e.g., teachers do not understand sensory sensitivities or autistic children's communication) *"School [thinks] they can put supports in place for learning and then remove them every 3 to 6 months as the students "should be getting better' no understanding of lifelong or that autism can present in a fluctuating manner i.e. can do this week and not next week."* (ID 357) *"I have colleagues who will say their classroom is quiet so a student doesn't need earmuffs, but the student has difficulty with noises like the air conditioner."* (ID 1430)	30%
2	**The school or learning environment is not designed for autistic students and/or is not sensory friendly** (e.g., sensory environment is overwhelming; lack of quiet spaces). *"It is a difficult thing to learn in an environment that is for example noisy - My son was placed in a class of 50 kids in a <location removed> mega class with [no] physical walls between another three classes of 24 children. School then had the mental gymnastics to state that the classroom was quiet for my autistic child with sensory processing difficulties."* (ID 85) *"Sensory issues in autism are not accommodated so autistic learners 'suffer' from noise, lights and overwhelming sensory inputs that non-autistic individuals may hardly notice."* (ID 482)	28%
3	**There is a lack of, or inconsistent use of, reasonable accommodation/adjustments** (e.g., accommodations not seen as beneficial for student; unwillingness to make adjustments). *"Proper understanding on what accommodations can and should be made for the child. there is a lot of autistic children missing out on appropriate accommodations because the teacher feels it is 'unfair' on the neurotypical children."* (ID 511)	23%
4	**Instructional approaches do not consider the needs of autistic children** (e.g., staff do not adjust learning tasks to meet individual needs; ambiguous language; too much information). *"For me, the instructions are vague and I have to make a lot of assumptions so if they would just make a little more effort regarding clear and specific instructions; I could complete the work without having to ask questions about what I am supposed to be doing."* (ID 830) *"The issues I faced were mostly confusion with what was being asked in assignments while at Uni. There were confusing terms like 'discuss' or 'explore' etc when I needed to write an essay. One thing that really helped me was to see a previous example or template so I knew how to structure my assignments."* (ID 98)	17%

5	**Pedagogy or assessment methods do not consider autistic cognitive profiles or differences** (e.g., autistic people may learn differently; standardised testing is inappropriate; group work is difficult) *"Education tends to be a "one size fits all". I for one take information in quite differently to most people."* (ID 541) *"Being expected to participate in a neurotypical way - I never liked speaking up in class or talking much but my teachers always forced me to and it made me highly uncomfortable."* (ID 1224)	15%
6	**Systemic expectations of schools, including rules, routines and attendance requirements, mean that schools are not genuinely inclusive for autistic students** (e.g., inflexible rules and expectations; rigid learning structures) *"There is a high level of cognitive effort that is required to adapt to a neuronormative environment and expectations, this can take a toll on my ability to process information and contribute to class discussions"* (ID 164) *"I work with a participant who was expelled from his private Autism specific school because of problematic behaviours. He was unable to be placed in a school for 12 months due to hand over issues, poor communication between the institutions and lack of external advocacy"* (ID 1121)	13%
7	**Curriculum is based on neurotypical standards and not suitable for, or sufficiently adjusted to, the learning needs of autistic children** (e.g., lack of choice for autistic children in the curriculum; lack of differentiation) *"Crowded curriculum means people like me who learnt my own way at the back of the classroom have less freedom to find their own way through learning at school."* (ID 77) *"Special interests are ignored, and opportunities to include autistic people are missed. We could run an entire lesson on our special interest but are constantly denied as it isn't part of the syllabus."* (ID 162)	12%
8	**Bullying and lack of school approach to prevent bullying** (e.g., bullying by peers or staff; hostility towards autistic student) *"Bullying - not just stopping the bullying, but facilitating processes that allow kids with ASD to be heard and understood (recognition that they can't respond the same way to neurotypical children and even communicating what has occurred is difficult"* (ID 100) *"I was frequently stalked, bullied and beaten at school, including a video recording of me being surrounded by a circle of violent kids threatening to kill me. The school refused to punish any of the perpetrators in the recording because I had a nervous laugh (another common ND trait) and said that I "must have been enjoying myself"."* (ID 1460)	11%
9	**Focus on behaviour, misinterpretation of behaviour and use of behavioural strategies** (e.g., being excluded from class due to behaviours; lack of understanding of behaviour as communication) *"Segregation, ostracism and humiliation due to hidden parts of our disability being seen as 'lazy' or 'fussy'. E.g., kids late to school due to sensory issues, and their 'favourite socks' feeling funny. Not their fault, and they shouldn't be punished or left out of school activities."* (ID 147) *"Being excluded from preschools, primary school, very poor behavior support, poor communication with parents. Some parents have reported that some schools use cages for behavior management!"* (ID 1337)	10%

10	**An insufficient understanding of, or support for, autistic student's social preferences or social interactions** (e.g., lack of social supports; neurotypical social expectations) *"Social difficulties - bullying, peer challenges, misunderstandings, difficulties arising from a strong sense of justice (i.e., 'dobbing', valuing fairness over harmony, etc)."* (ID 737) *"Not enough adults that understand the Double Empathy Problem, i.e., the difference between the two types of meaning-making systems typically used by neurodivergent and neurotypical people, thus negatively influencing social experiences at school."* (ID 1195)	10%
11	**School impacts mental health of autistic students, which can lead to masking** (e.g., anxiety; stress) *"My son found school very difficult and ended up leading to mental health issues in his teens."* (ID 525)	9%
12	**Lack of training and education about autism** (e.g., teachers are not trained to understand autism; poor quality autism PD) *"Teachers not trained in how to teach an autistic child in a way that works. My son is 9, but is at a 5 year old level and hasn't improved at all in the last two years at school."* (ID 20) *"The teachers have not been trained to understand or assist children with autism. If the teachers do have a little understanding it is usually what they have "picked up" in a general manner"* (ID 452)	8%
13	**Communication styles and preferences of autistic people not understood** (e.g., neurotypical communication seen as gold standard; lack of awareness of communication styles of autistic children). *"Neurotypical communication being seen as the 'gold standard' of communication, rather than advocating and embracing differences."* (ID 30)	7%
14	**Autistic children are excluded and/or isolated; difficulty making friends** (e.g., peer exclusion; social isolation) *"Peer exclusion leading to isolation and feelings of profound loneliness."* (ID 868) *"I had no academic challenges but not fitting in socially with peers, feeling constantly confused by their words and actions, realising being different was a bad thing and being bullied for loving learning and giving 100% caused deep suffering and loneliness."* (ID 1452)	7%
15	**Lack of patience, empathy, care or understanding (including ableism, mistreatment, stigma and discrimination)** (e.g., lack of access to teachers/staff with genuine care; student and family being discriminated against) *"Many lecturers/tutors cared little for accessibility and sometimes would even intentionally sabotage it (like muting mic to give additional information for students who "cared enough to show up physically for lectures")."* (ID 786)	7%
16	**Education system is under resourced** (e.g., classes are too big; unrealistic staff to student ratios in mainstream settings) *"Feel like schools have rationalised chaos and high pressure for children to a degree - little time or space or support for teachers to reflect on children's experiences, and how to make it less stressful."* (ID 183) *"Teachers are so much under pressure and have so many demands that they may not have capacity to do the things they know work."* (ID 411)	6%

Question 2: What do you think is causing these problems and sample quote from responses?

Rank	Factors causing the problems experienced by autistic people in relation to education and sample quotes from responses	% of all respondents who stated this issue
1	**Educators and educational leaders lack awareness and understanding about autism and associated needs (including learning needs)** (e.g., poor/limited understanding of autism; lack of understanding of the challenges experienced) *"Level of knowledge about autism amongst educators varies wildly and many have very little knowledge or experience in how to work with autistic students."* (ID 18) *"Not every teacher can be a speech therapist, but a greater understanding of communication and emotional needs of people who are neurodivergent would move towards an environment that fosters greater levels of education accessibility."* (ID 668)	28%
2	**Lack of training in autism via university and/or professional development** (e.g., lack of special needs trained teachers; lack of professional development on autism) *"Educators are not provided with appropriate training on supporting autistic children within the classroom and have to "learn on the job"."* (ID 303) *"Lack of training which results in children being seen as a deficit and it is a problem to have to try and teach them."* (ID 495)	24%
3	**Education system designed for neurotypical children resulting in challenges with both mainstream and segregated settings in meeting the needs of autistic children** (e.g., education is based on neuronormative brains and autistic brains have to adapt; education system is not adapted) *"The push for inclusion that forces all students including autistic students to be put together in the same learning environment and then expecting that all students will thrive in that same environment."* (ID 337) *"The way the mainstream education system has been built without regard to the needs of autistic people and pushes people whose brains and bodies work differently out. We now need to transform this system that has evolved this way for a long time and has entrenched exclusion."* (ID 707)	21%
4	**Funding and resources for autistic students' educational needs are insufficient, difficult to access and poorly distributed** (e.g., funding is prioritised some autistic students (e.g., level 2) but not others (e.g., gifted), funding can be mishandled or pooled with other students with disabilities) *"Approach/process in determining whether a student/school gets additional funding from the DET is difficult for the school and families to navigate. It is also very time and resource intensive and families and schools do not necessary have the knowledge and time to address the process."* (ID 714) *"Lack of funding for schools to provide even basic supports and reasonable adjustments to a child in the classroom."* (ID 914)	19%
5	**School environments are not designed for inclusion of autistic students** (e.g., schools are loud; lack of sensory-friendly environments).	11%

	"Re sensory issues - lack of understanding e.g., a (female) kid could prefer clothing that feels secure but uniform is a loose fitting dress. Only alternative option appears to be boys uniform but this has other social implications." (ID 897) *"Lack of understanding and/or flexibility to accommodate changes to the sensory environment for autistic people. e.g., noisy corridors, not providing learning alternatives to participating in swimming carnivals (strong smells and noise), not providing accommodation alternatives on school camps to noisy bunk rooms"* (ID 1131)	
6	**Accommodations and supports for autistic students are insufficient, and the capacity, knowledge and resources required to accommodate/support autistic students are lacking** (e.g., lack of ability/capacity to make accommodations; lack of understanding how to support students). *"I think a lack of flexibility around school rules and providing accommodations often comes from school staff not having adequate understanding/knowledge of autism (e.g., treating a student's sensory sensitivity as a behavioural problem they can choose not to do, or a student getting in trouble for not demonstrating "whole body listening" rather than recognising they may find it easier to listen without making eye contact)."* (ID 817) *"There are tens of thousands of Non Verbal Autistic school students across the country, particularly in special schools who have NO means to communicate. Often, NO individualised AAC (high tech or low tech) & most teacher, special ED & assistants or aides aren't familiar with using an AAC's & the rights of the child to communicate, ALL day, every day, across every domain."* (ID 925)	10%
7	**Teachers are unsupported and overworked** (e.g., educators are time poor, under resourced, and overloaded) *"Education staff are overworked, underpaid, and given no incentive to pursue continuous professional development opportunities."* (ID 532) *"Teachers don't have the time or the resources to support Autistic individuals and find it overwhelming. In many conversations with teachers they are typically empathetic and want to help, however they become exhausted because they find they can't do the things they need to do properly and so what they are able to do doesn't work"* (ID 1006)	10%
8	**Teaching methods, learning activities, content, or assessment may not be suitable for autistic children, or accommodate their needs** (e.g., pedagogy is one-size-fits-all; teaching methods don't take into consideration challenges of autistic children (e.g., co-occurring ID). *"A lot of vital information is given verbally during lectures and our processing is different. It can be hard to figure out what information is needed or how to capture it all while the lecture is happening."* (ID 330) *"Graphic/visual representations are really hard to get right but really important for students with certain learning styles as they might not function as just a "reminder" of the concept the way it does for most, but to re-explain concepts over and over again that we fundamentally understand but cannot articulate well without prompting."* (ID 821)	9%
9	**Lack of society or community education about or acceptance of autism** (e.g., poor societal attitudes towards those who are divergent/different; societal unwillingness to change attitudes). *"A dominant narrative of autism which is driven by non-autistic voices who are given disproportionate media coverage in relation to autistic issues."* (ID 343)	8%

	"Social narrative around Autism being a disease or condition requiring cure instead of focusing on removing barriers to quality of life, celebrating strengths and being pro-autism in our acceptance of autistic people." (ID 1020)	
10	**Lack of understanding of the heterogeneity of autism in terms of profile and needs** (e.g., reliance on stereotypes; lack of awareness of the diversity of autistic students). *"Poor understanding of ASD and its highly variable presentations (e.g., interpreting some as oppositional), especially in biological females"* (ID 677) *"Every person is different on the Autism Spectrum. Why tick one box when there are millions to tick. Not all Autistics are the same."* (ID 863)	7%
11	**Peers and others lack understanding of autistic social styles and preferences** (e.g., double empathy problem; communication breakdown between autistic and non-autistic students). *"A lack of education for non-autistic children on how autistic people socialise. If there's no middle ground, all the pressure is put onto the autistic person to cross the divide in communication style which is a lot of energy and effort, which could otherwise be used to learn and participate in education."* (ID 21) *"Lack of education to children about neurodiversity - bullying is a recognized problem, but still not enough is being done to educate neurotypical children."* (ID 975)	7%
12	**Ableism/stigma/othering/safety/lack of tolerance/judgement** (e.g., ableist conceptions and design of schools; opportunistic and oppressive treatment of autistic people). *"Discriminatory attitudes towards children who display behaviours of concern"* (ID 1052)	7%
13	**Teachers hold negative attitudes or having a lack of compassion towards, or interest in, autistic students.** (e.g., lack of care from mainstream education; lack of interest). *"I would say lack of awareness and understanding, but schools are given so many opportunities to learn that I can't help but feel that there is a lack of interest in understanding and supporting, from some teachers, certainly not all"* (ID 471)	7%
14	**Schools not communicating/collaborating with allied health professionals/disability services.** (e.g., schools need to allow more allied health visits to autistic students; to collaborate and consult with allied health professionals more). *"Lack of resources (including time) for allied health professionals to teach teachers and school staff about how to use AAC."* (ID 170)	6%
15	**Class sizes are too large, the student to teacher ratio is poor and schools are understaffed** (e.g., class sizes are too large; not enough staff or support staff). *"Outdated models of schooling - 1 teacher per class with limited or no access to team teaching and support from properly trained/qualified specialist teachers"* (ID 703) *"Class sizes are too large. One teacher is expected to manage a class with several children individualised needs and this is an unrealistic expectation and quality education is not provided."* (ID 998)	6%

16	**Schools are often focused on behaviour and behaviourist strategies** (e.g., focus on behaviour rather than underlying needs; behaviour management strategies are reactive/punitive). *“Thinking we are behaving badly just for the fun of it etc. Concentrating on how we "disturb" other people's lives instead of seeing how and why we are having a hard time.”* (ID 342) *“It doesn't help that because school is an extremely stressful environment for autistic children, they are often materially disruptive to classrooms, and so teachers see them as a problem that needs to be fixed, rather than as a person in a fragile emotional state.”* (ID 784)	6%
17	**Government, education departments and school leaders have not prioritised inclusion of autistic students.** (e.g., there is a lack of consequences for not following policy) *“Lack of understanding by Principals and the education department to know that students with ASD, have the "right" to an inclusive education to reach their full potential and to have the same rights as other neurotypical students.”* (ID 171) *“Lack of oversight and accountability. Until there is something like a Disability Education Commissioner which can proactively investigate breaches and misconduct, educational institutions will continue to other-ise autistic students, cover up bullying, and mistreat disabled students as a whole.”* (ID 1433)	5%
18	**Support is lacking for undiagnosed autistic students, and diagnosis is delayed by wait times and teachers’ inability to recognise diverse autistic presentations** (e.g., delayed diagnosis; diagnosis increases access to supports in school). *“School does not understand that if a child has autism, that their simple screening in the school setting does not reverse a diagnosis made by clinical psychologist/speech pathologist/paediatrician”* (ID 484) *“Access to timely assessment processes within the public system to support students with autism and educators. It can take years, particularly in regional areas. Until diagnosis is formalised, access to funding both through the education system and via NDIS leaves people struggling longer than necessary.”* (ID 797)	5%
19	**Autistic students mask or conform to neurotypical standards** (e.g., expectations of autistic students to mask and conform; forcing neuro-normative behaviours and expectations on children). *“The dominant deficit-based view of Autism being that Autistic children should be encouraged to conform socially and academically, rather than be valued intrinsically for their differences.”* (ID 290) *“You make the child attempt to make all the change - psychologists, OT, Speech therapy - then wonder why they are so anxious and unhappy. They can't be their true selves.”* (ID 599)	5%

Question 3: What do you think could prevent or reduce these problems and sample quote from responses?

Rank	Factors that could prevent or reduce the problems experienced by autistic people in relation to education and sample quotes from responses	% of all respondents who stated this issue
1	**Increasing pre-service and in-service training on autism for all school staff, and especially for educators** (e.g., training for staff/teachers/lecturers/tutors; training in university). *"Increased PD for ALL educators on the broader issues of neurodiversity, most notably its heterogeneity and that one strategy is not EVER appropriate for EVERY student"* (ID 354) *"Making PD on the issues that Autistics have with accessing appropriate education, and solutions, compulsory for all educators."* (ID 385)	41%
2	**Increasing educator and broader community awareness and acceptance of autism, and treating autistic students with respect, kindness, tolerance and empathy** (e.g., teach acceptance rather than trying to change neurodivergent individuals). *"Public education and awareness programs to increase understanding of the diversity of autistic experience."* (ID 343)	18%
3	**Increased and improved funding and resources to provide autistic students with the staff and environment they need for an equitable learning experience** (e.g., funding to address sensory environment (light/sounds/sensory rooms); funding for teachers' aides). *"Funding should be provided to schools to address the sensory aspects of the environments e.g., sounds, light, quiet spaces, sensory rooms"* (ID 14) *"Better funding for LEARNING issues. Such as tutors at School or experienced Teacher Aides and give them the time they actually have been assigned for that child"* (ID 793)	18%
4	**Actively consulting and collaborating with autistic and neurodivergent people, and employing more autistic teachers, consultants, policy/curriculum planners and leaders in education** (e.g., ask autistic people what they need and implement this; autistic input into school building design). *"It should be a requirement that a certain percentage of staff fly under the neurodivergent flag themselves. Not only does this lend an autie voice to the situation academically speaking (thus supporting the different ways auties learn or require support), it provides openly proud auties to be role models for not only ND children but also to NT children which can only lessen bullying and promote acceptance"* (ID 63) *"Inclusion of the autistic voice as standard. Not 'increased" Inclusion - this should be a non-negotiable prerequisite. "Nothing about us without us.""* (ID 68)	15%
5	**Ensuring schools are designed to minimise sensory overwhelm and include spaces that autistic people feel safe and comfortable** (e.g., environment modifications; quiet spaces enabled by universal design principles).	13%

	"A purpose built sensory room in every school, where autistic students can go to have some quiet time." (ID 530) *"Foster a more relaxed learning environment that is not the traditional desk set up. Allow the students to go to a safe place when needed whether it's outside or in an area in the room."* (ID 594)	
6	**Reducing class sizes and increasing the number of teachers and aides/support staff in classes** (e.g., reducing class sizes benefits everyone; more aides for autistic students) *"If schools reduced class sizes this would produce a lot of welcome change and opportunity. Reducing class sizes benefits everyone - students, teachers and other staff, as well as anyone in those cohorts who also happens to be autistic or neurodivergent."* (ID 72)	11%
7	**Adapting pedagogy, instruction and assessment to better meet the needs of autistic students** (e.g., neurodivergent pedagogy will benefit all students; permit alternative assessment types) *"Develop autistic style teaching methods"* (ID 477) *"Making educational content available in a range of contexts - lectures, videos, readings, images, hands on doing."* (ID 664)	11%
8	**Increasing and improving education, information, and research on autism** (e.g., additional autism research; neurodivergence education). *"More research should be done with diverse communities to better define Autism and give a clearer picture of this neurodivergence."* (ID 767) *"Educate the wider community about autism, break down the fear and stigma associated with a diagnosis"* (ID 1443)	11%
9	**Increased collaboration, communication, and planning between autistic students and their parents, teachers and allied health team** (e.g., listen to parents as they are experts on their child; all stakeholders planning together). *"More in depth conversations with parents/guardians/students with a carefully chosen team so that parents aren't having to explain everything to each teacher every term for the rest of the schooling life. It's exhausting, particularly for parents who are autistic."* (ID 1081) *"Establishment of better and more regular avenues of communication between school teachers, service providers and families."* (ID 1542)	11%
10	**Increasing accommodations/individual plans for autistic students, as well as understanding of how and why to make these accommodations** (e.g., allowing personalised adjustment (not standard adjustments); information for teachers on what accommodations autistic students may need and why they are important). *"Allowing adjustments that are meaningful and personalised to actually help the individual rather than just selecting standard adjustments."* (ID 41) *"Information made available to educational professionals as to the likely requests from NDs for alternative treatment, and the reasons why such requests are not simply special pleading, but in fact a [sensible] way of assessing the true capabilities of NDs."* (ID 308)	10%
11	**Providing multiple options for education settings and or educational options** *"True inclusion - ensuring Autistic child can regulate at school and in the classroom. Not outside or at home. Outside the classroom is called exclusion."* (ID 359) *"Changing the education system to make it more flexible and inclusive."* (ID 533)	10%

12	**Government/school leadership initiatives to reduce stigma and tackle discrimination** (e.g., change in education policies so all students are supported; leadership committing to embracing diversity; government legislative changes). *“Leadership is not fully versed in the DDA [Disability Discrimination Act] and DSE [Disability Standards for Education] - they should have to pass a compulsory training and assessment on it every couple of years the same as we do CPR and Protective behaviours.”* (ID 50) *“Mandatory reporting to outside authority if incidences of restraint and seclusion.”* (ID 349)	9%
13	**Adapting or developing the curriculum to enable autistic students to have choice, to study their interests, and to have their learning needs met** (e.g., re-imagining of the curriculum to be delivered through student directed learning; appropriate curriculum for those with intellectual disability). *“Allowing autistic people to create learning opportunities based on special interests.”* (ID 91) *“Embedding understanding of invisible disabilities into curriculum, with concepts such as different ways of communicating, different ways of socialising, different ways of learning etc.”* (ID 166)	7%
14	**Increasing student access to autism diagnosis** (e.g., fast track diagnosis; changes to assessments to reflect heterogeneity of autism profiles). *“Free diagnosis/functional assessments, etc.” (ID 288)*	7%
15	**Supporting educators to build relationships with, and meet the needs of, autistic students** (e.g., support for teachers to meet the needs of autistic students; support for staff and students; teachers need more support to develop relationships with autistic students). *“Ensuring teaching staff are supported through understanding and modelling inclusion in education”* (ID 188) *“Focus on connection between teacher and student so that they can pick up early cues and prevent issues rather than react once it's too late”* (ID 929)	6%
16	**Teaching all students about autism and autistic communication styles, in a neutral way, just as education is provided about cultural diversity** (e.g., teaching about different communication styles; bridge and understand differences). *“Greater education about neurodiversity at a young age in the same manner that cultural differences are explicitly taught.”* (ID 74) *“Double empathy - teach all children from a young age about accepting the differences in neurobiology and that everyone is equal not less - everyone needs to learn about differences in communications styles and that one is not better than the other - just different”* (ID 535)	6%
17	**Increasing flexibility around delivery and enrolment options for autistic students** (e.g., flexibility for part time enrolment for autistic students; flexible delivery options (i.e., learn from home). *“More flexibility for kids with autism for part time enrolment or project-based learning.”* (ID 194) *“Our daughter needed to get to the point that she was extremely depressed and suicidal, self-harming before we could access distance education. It was very distressing and traumatic and she has been working to find herself for the last 3 years at Sydney distance high school”* (ID 357)	5%

18	**Using collaborative and supportive behaviour strategies and understanding reasons for behaviours** (e.g., teach kids to regulate instead of focussing on behaviour; develop affirming terminology/techniques for behaviour support). *“Behaviour management - develop supportive crisis strategies to reduce distress instead of punishment and trying to repress negative behaviour”* (ID 81) *“So many behavioural issues are resulting from teachers not understanding the [sensitivities] that neurodivergent people have or their learning styes.”* (ID 753)	5%

Question 4: What is working well, or has worked well, in relation to autistic people in education?

Rank	What is working well, or has worked well, for autistic people in education, and sample quotes from responses	% of all respondents who stated this issue
1	**When educators have knowledge about autism, value autistic students and treat autistic students well** (e.g., when educators have positives attitudes towards autistic students; when autistic students are valued intrinsically and not pressured to conform or change) *"Individual educators who care and have lived experience"* (ID 1545) *"As a professional advocate who often delivers PD on Neurodiversity to teachers, I am seeing an increasing number of them who are pretty passionate about learning more, and I am always very enthusiastic in affirming this when I meet them."* (ID 1467)	34%
2	**When accommodations are made, and autistic students are supported at school** (e.g., when accommodations are made for autistic students around assessments/environment/curriculum; accommodations for communication methods). *"Adaptations to assessment and curriculum that are person-centred and respond to the individual communication and sensory needs of the student."* (ID 1521) *"There is now a greater focus on accommodations and an awareness of the challenges for autistic people via personalised learning plans."* (ID 151)	24%
3	**When the curriculum, pedagogy and instruction methods are tailored to autistic students' needs** (e.g., being flexible around learning processes; ensuring instruction is clear and direct). *"Educators who…acknowledge that ND individuals learn differently and that can include needing to move, sensory changes, and executive functioning support"* (ID163) *"For my child, child-directed learning. He learns an incredible amount but not in 'conventional' ways."* (ID 1170)	18%
4	**When attitudes or approaches to supporting autistic students are positive or neuro-affirming** (e.g., when positive attitudes are taught to students; positive attitudes towards behaviour). *"Higher profile/raised awareness of autism through campaigns, charitable works, celebrities (e.g., Chloe Hayden) and media (e.g., TV shows like The A Word or Atypical)"* (ID 673) *"I think peers are getting better at understanding their Neurodiverse peers (bullying aside). This doesn't help the students who don't openly identify as Autistic/ ND, but I believe that student peer attitudes are shifting somewhat."* (ID 1157)	17%
5	**When education institutions, health and disability professionals, autistic adults and families collaborate to support and listen to the autistic student** (e.g., collaboration with the autistic student, all stakeholders, allied health professionals, educators, autistic adults, parents). *"Timely, regular, clear, concise communication and shared goals between educational staff, parents and support personnel (therapists, support workers)."* (ID 654) *"IEP meetings where the student is present and is empowered to speak for themselves and is seen as capable of doing so and is listened to. [This] began to happen from about year 9, for my [oldest] child, to a degree."* (ID 1419)	16%
6	**When the physical environment is adapted to autistic sensory needs** (e.g., better access to low sensory spaces/break out spaces).	14%

	"My art teacher let me sit in the art room by myself during lunch times. [I] could unmask, and either have a space where I could more easily focus on my assignments, or where [I] could be creative." (ID 70) *"Classrooms that have a quiet space, allow fidget toys and movement breaks, dimmer lights, have visual [schedules], allow noise cancelling headphones, allow alternative to school uniforms and school shoes if their is a sensory issue around clothing."* (ID 427)	
7	**When learning delivery structures, modes and locations suit the autistic student** (e.g., when delivery modes and locations are flexible and suit the autistic student, including flexible/non face-to-face delivery modes/off campus and distance locations). *"Online/self paced learning has been amazing for myself and many Autistic people I know. It allows engagement as a pace that suits us and revision of verbal instruction is easier. There is less energy spent on masking and putting up with the barriers and more on learning the content."* (ID 772) *"Managed attendance - acknowledging that education is exhausting for students and allowing managed attendance is consultation with families"* (ID 702)	13%
8	**Nothing/not much/unsure** *"Not much to be honest. Mostly these are bandaid strategies that work for that environment at a superficial level. This causes other problems later in life because real skills are not developed - lower rates of employment, education, etc. and social isolation, anxiety, depression, misdiagnosis, suicide, and all sorts of other damage."* (ID 627) *"Nothing has worked for me. I spoke to the teacher, spoke with the co-ordinator, wrote letters. nothing was done and they shrugged it off."* (ID 1039)	12%
9	**When autistic students' education is supported by policies, laws, leadership and/or funding** (e.g., specific policies such as the Disability Act and Victorian Disability Inclusion Policy) *"Some progress in policies recognising that support for disabled students needs to extend beyond the classroom and include the school environment and participation more broadly (as seen in the recent Victorian Disability Inclusion policy)"* (ID. 246) *"The principal of his school is passionate about supporting people with disabilities to achieve equitable access to the curriculum, and achieve their goals."* (ID 1251)	12%
10	**When the education system works for the autistic student** (e.g., increased discussion around school systems for autistic students; availability of different school systems). *"At the time he was in year 9 it was recognised he was struggling both socially and academically and was finally removed from the mainstream classes and placed in Special ED class where he started thriving at long last. This recognition should have come much earlier."* (ID 1119)	11%
11	**When class sizes are small and autistic students have 1:1 support form staff** (e.g., small classrooms, 1:1 support/teaching). *"My daughter's Autistic primary school is amazing. They have small class sizes (6-8 kids with a teacher and 2 assistants)."* (ID 489) *"Individual educators who took the time (even if stretched resource-wise) to spend the time one-on-one for my child to learn and then once he had learned in an individual setting away from others, he could then apply this learning with his peers."* (ID 831)	11%

12	**When autistic students are supported to form strong social relationships at their place of education, free from bullying and criticism** (e.g., connecting with non-autistic peers, connecting with autistic peers). *"In situations where autistic people come together and learn with each other they can often help each-other."* (ID 218) *"Being grouped with friends (safe people) or with others who either like to stim loudly like us, or are sensory avoiders like us. Basically to work with peers who have similar tolerances for sensory stimuli."* (ID 1097)	9%

Appendix E-2: Umbrella review search terms

The following search terms were used for the respective databases:

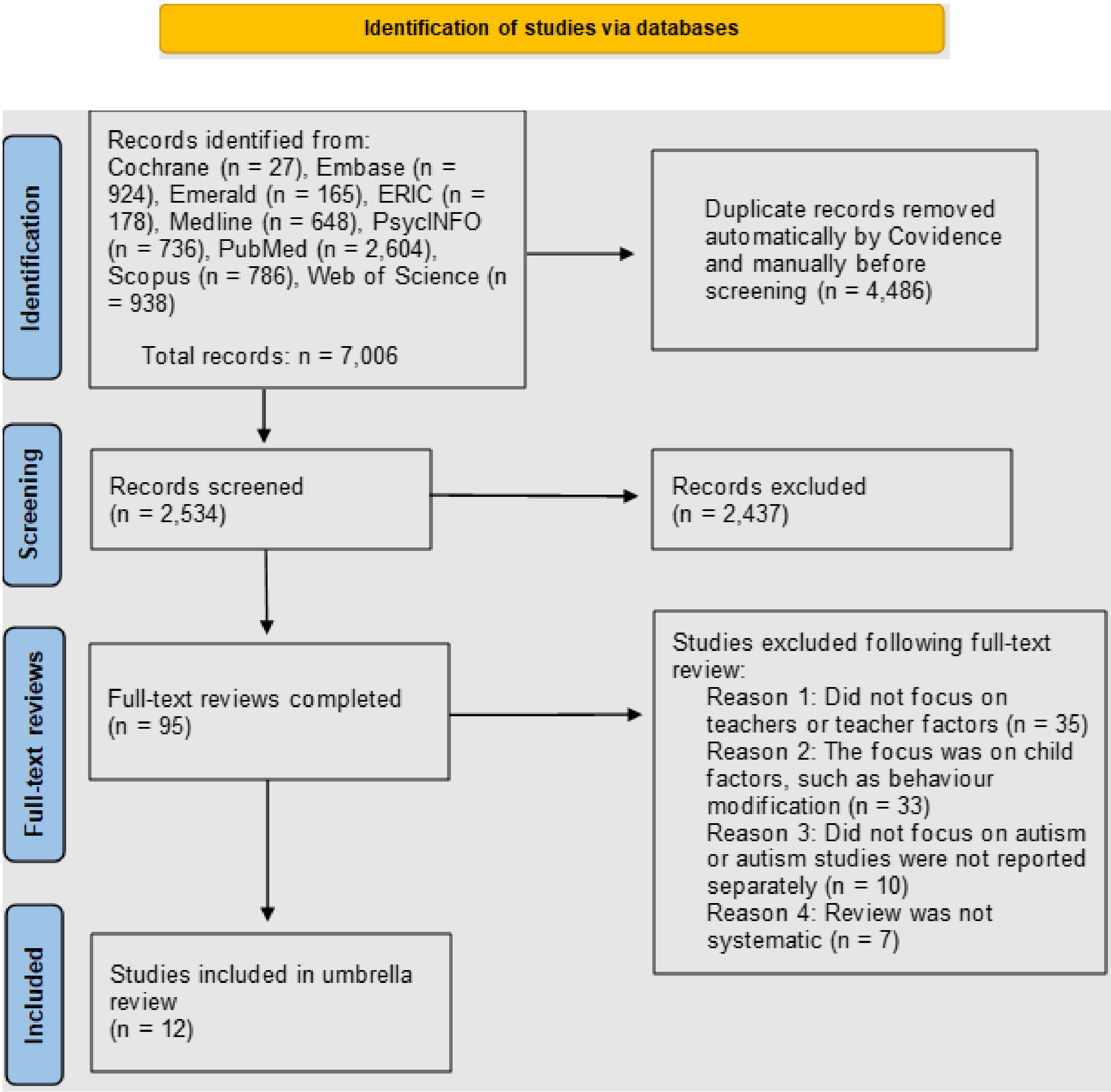
Cochrane, Embase, Emerald, ERIC, Medline, PsycINFO, PubMed, Web of Science

(autis* OR ASD OR ASC OR Asperger* OR pervasive developmental disorder OR PDD) AND (systematic review* OR scoping review OR narrative review OR systematic literature review* OR systematic quantitative literature review OR evidence synthes* OR meta-analy* OR meta-regression*) AND (teacher* OR assistant* OR coach* OR educat* OR trainer* OR instructor* OR tutor* OR school OR class OR inclusi*) AND (belief* OR perception* OR attitude* OR confidence OR self-esteem OR self-efficacy OR self-concept OR competence OR attitude* OR perspective* OR awareness OR knowledge OR pedagog* OR approach* OR teaching method* OR strateg* OR practice* OR instruct* OR support* OR program* OR accommodat* OR modif* OR adapt* OR adjust* OR develop* OR training OR professional development OR teacher education)

Scopus

(autis* OR ASD OR ASC OR Asperger* OR “pervasive developmental disorder” OR PDD) AND (“systematic review*” OR “scoping review” OR “narrative review” OR “systematic literature review*” OR “systematic quantitative literature review” OR “evidence synthes*” OR meta-analy* OR meta-regression*) AND (teacher* OR assistant* OR coach* OR educat* OR trainer* OR instructor* OR tutor* OR school OR class OR inclusi*) AND (belief* OR perception* OR attitude* OR confidence OR self-esteem OR self-efficacy OR self-concept OR competence OR attitude* OR perspective* OR awareness OR knowledge OR pedagog* OR approach* OR “teaching method*” OR strateg* OR practice* OR instruct* OR support* OR program* OR accommodat* OR modif* OR adapt* OR adjust* OR develop* OR training OR “professional development” OR “teacher education”)

Appendix E-3: PRISMA diagram



Records identified from:
Cochrane (n = 27), Embase (n = 924), Emerald (n = 165), ERIC (n = 178), Medline (n = 648), PsycINFO (n = 736), PubMed (n = 2,604), Scopus (n = 786), Web of Science (n = 938)

Total records: n = 7,006

Duplicate records removed automatically by Covidence and manually before screening (n = 4,486)

Records screened
(n = 2,534)

Records excluded
(n = 2,437)

Full-text reviews completed
(n = 95)

Studies excluded following full-text review:
Reason 1: Did not focus on teachers or teacher factors (n = 35)
Reason 2: The focus was on child factors, such as behaviour modification (n = 33)
Reason 3: Did not focus on autism or autism studies were not reported separately (n = 10)
Reason 4: Review was not systematic (n = 7)

Studies included in umbrella review
(n = 12)

(Template from Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D et al. (2021). The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. *BMJ, 372* (71). doi: 10.1136/bmj.n71)

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Tomlinson, C., Bond, C., & Hebron, J. (2020). The school experiences of autistic girls and adolescents: a systematic review. *European Journal of Special Needs Education*, *35*(2), 203–219. https://doi.org/10.1080/08856257.2019.1643154

Appendix F: Postsecondary education

Appendix F-1: Umbrella review search terms

Databases Searched

(title, abstract, and key words)

- Cochrane
- EMBASE
- ERIC
- Emerald
- Medline
- PsycINFO
- Pubmed
- Scopus
- Web of Science
- Google scholar

Search Terms

The following search terms were used to identify relevant articles

Autism	Review	Postsecondary Education
autis* OR ASD OR ASC OR Asperger* OR “pervasive developmental disorder*” OR PDD	“systematic review*” OR “scoping review*” OR “narrative review*” OR “systematic literature review*” OR “systematic quantitative literature review*” OR “evidence synthes*” OR meta-analy* OR meta-regression*	University OR college OR “vocational training” OR apprentice* OR “tertiary education” OR “postsecondary education” OR “post-secondary education” OR “post secondary education” OR “higher education” OR “further education” OR TAFE OR “Technical and further education” OR synthes*” OR meta-analy* OR meta-regression* "third-level education" OR undergrad* OR postgrad* OR "vocational school*" OR "trade school*" OR "tech* school*"

Inclusion and exclusion criteria

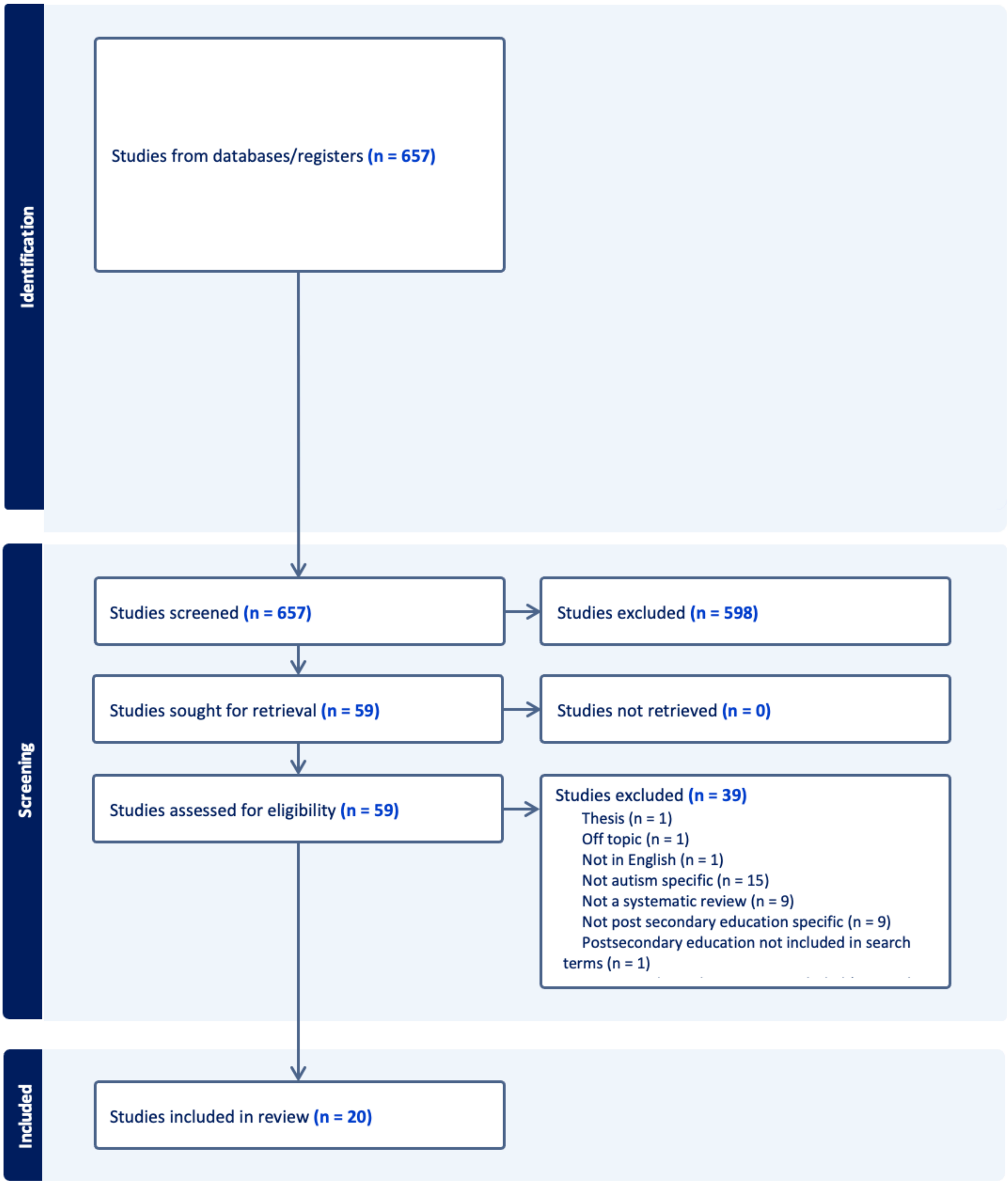
General **inclusion criteria** are below. The study must meet all of these to be included.

1. The article reports on a review of the literature that was undertaken systematically. A review will be considered “systematic” if it: (1) includes a clear statement of the purpose of the review; (2) describes the search strategy (i.e., key search terms, multiple relevant databases, specification of search limits); (3) indicates the criteria used to select studies for inclusion; and (4) presents all findings relevant to the main purpose of the review
2. The article must focus on autistic (human) participants, or if it is part of a review on broader conditions, the articles on autistic human participants must be reported on separately
3. The article must report on articles relating to an aspect of employment
4. The article must be published in a peer-reviewed journal.

The **exclusion** criteria are listed below. A study only needs to meet one of these criteria to be excluded:

1. Articles or reviews that do not meet the criteria to be considered “systematic” (for example (for example, narrative and unstructured reviews, primary studies, opinions, commentaries, letter, book chapters, conference abstracts or editorials)
2. Umbrella reviews, rapid reviews, or “reviews of reviews”
3. Reviews that do not focus on autism, do not report autistic participant studies separately or do not report on human studies.

Appendix F-2: PRISMA diagram



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Appendix G: Employment

Appendix G-1: Content analysis categories

Question 1: What are three problems that autistic people experience with employment?

Rank	Problems experienced by autistic people in relation to employment and sample quote from responses	% of all respondents who stated this issue
1	**Experiencing discrimination, stigma, stereotyping, and bullying** (e.g., Autistic people are suffering discrimination, stigma, stereotyping and bullying because of their autism and this is affecting their ability to gain and/or maintain employment) *"Discrimination in the workplace. Employers will not accept difference as a part of the application process, and if they do, you are shoved into some sort of "autism appropriate" occupation."* (ID 935)	31%
2	**Access to flexible work environment and supports from employers** (e.g., Autistic people are having difficulty accessing supports or flexibility in the workplace that enable them to work well.) *"Workplace accommodations that are being asked for are being denied, ignored or "forgotten" about."* (ID 162) *"Lack of freedom in some workplaces to do work in way that suits (e.g., everyone having to do work in same way and in same place rather than having freedom to work in quiet space or in way that still gets job done but feels more natural to the autistic person)."* (ID 1022)	30%
3=	**Challenges of navigating the neurotypical socialisation governing workplaces** (e.g., It can be difficult for autistic people to "fit in" at work because the way they communicate and socialise may be different.) *"Being misunderstood, and considered 'rude' in the workplace, for example from not saying hello to everyone in the morning, or being too blunt with others."* (ID 1322)	27%
3=	**Lack of understanding about autism and the capabilities and needs of autistic people** (e.g., Many employers and co-workers have very little knowledge about the strengths and needs of autistic employees.) *"Very little understanding concerning autism with employers."* (ID 452)	27%
5	**Navigating how to find a job and its related processes** (e.g., attending interviews etc, can be challenging when you may not communicate and behave in the same way as neurotypical people.) *"Speaking for myself, getting though an interview to get a job felt like a major challenge, why I haven't changed companies in many years. Small issues for social norm like struggling with eye contact and small talk through to talking about self and thinking on the spot, topped off with rejection sensitive dysphoria."* (ID 911)	24%

6	**Workplaces not suitable for autistic people** (e.g., Autistic people often feel uncomfortable in their workplace) *“Environmental barriers such as open plan offices, noisy and bright environments, no options for low-sensory spaces to work in or have breaks in.”* (ID 1494)	12%
7=	**Workplace not accommodating for sensory issues** (e.g., The sensory issues of autistic people are not taken into account and accommodations are not always made by employers.) *“Working environments are not set up to accommodate individuals with sensory issues (uncomfortable chairs, loud music, open offices, fluorescent lights.”* (ID 1215)	10%
7=	**Keeping a job and meeting its requirements** (e.g., Autistic people may have challenges in keeping a job and meeting the usual requirements expected of employees.) *“Maintaining employment due to demands that lead to Autistic burnout living.”* (ID 1330) *“Work schedules not accommodating for periods of regulation after intense periods of high social demand.”* (ID 602)	10%
9=	**Lack of training about working with an autistic person** (e.g., Most employers and work colleagues do not have any training in how to interact and work with autistic people.) *“Employers/Employees not taking the time to actively listen, learn and understand the person, how they see things.”* (ID 1285)	9%
9=	**Limited job opportunities for autistic people** (e.g., Job opportunities for autistic people may be limited.) *“Hard to get employed sometimes due to many reasons such as presenting awkward/shy/weird in interviews, or feeling anxious to apply for jobs in fear of the unknown- in my case, it was easy to get employed for a job I applied for but I found that I burnt out very quickly and had to quit after 6 months”* (ID 1472)	9%
11=	**Workplace demands being incongruent with autistic traits** *“Their honesty makes them enemies of co-workers and superiors because they are unaware of the social hierarchy, and don’t understand that people take offence at honest evaluations of reality, which is observed by the autistic outside the social awareness that their truthful evaluation of reality puts others and their performance in question.”* (ID 469)	8%
11=	**Fear of disclosing diagnosis** *“People with autism find it hard to disclose being autistic when apply to and maintaining employment still. As Employers still see people with autism as being a liability, and should be treated as such. This can lead to having people with autism being let go or not being hired because of reasons related to their disability but not strictly their disability.”* (ID 940)	8%

13=	**Getting a job – lack of support or practical guidance** *“In my experience with master 19, there are no specific strategies in place to help him get a job, no training or prospects, no workplace training or anything. His CBS COMMUNITY BRIDGING PROGRAM, are not tailored to his needs.”* (ID 1350) *“Not enough support people for extended periods of time to support the people transitioning into the workforce.”* (ID 1331)	7%
13=	**Deficit-based model/ people are dismissive of abilities** *“Colleagues and superiors underestimating our abilities due to our behaviours such as stimming.”* (ID 1297) *“Not being competitive with job applications, neurodiversity is generally not seen as an advantage and a judged as less desirable in interviews or from resumes (if it is mentioned).”* (ID 180)	7%
13=	**Burn-out and fatigue** *“Burnout from working multiple days in a row.”* (ID 1097)	7%
16	**In the job: lack of communication ,task instructions from management/work** *“Lack of clear communication eg work requests are implied.”* (ID 245)	6%
17=	**Selection for advancement - leadership/ management roles** *“Much of promotions/salary increases is not tied to actual performance but more to ‘How good can someone bargain’, ‘How good can they sell themselves’, ‘How much are they liked by their superior’).”* (ID 374) *“Performance reviews and management which are biased towards neurotypical staff.”* (ID 481)	5%
17=	**Fitting in – Masking** *“Masking to appear neurotypical causes burnout.”* (ID 51) *”Burnout due to masking - Lack of understanding in the workplace (communication differences, uniform requirements, etc).”* (ID 288) “*Having to mask to look normal rather than being able to show passion.”* (ID 1169)	5%

Question 2: What do you think is causing these problems?

Rank	Factors causing the problems experienced by autistic people in relation to employment and sample quote from responses.	% of all respondents who stated this issue
1	**Lack of understanding, awareness or acceptance of autistic people, leading to ignorance and misinformation** (e.g., There is a general lack of understanding, awareness and acceptance of autism in the community. This leads to ignorance and misinformation being perpetuated in the workplace.) *"Ignorance and stereotyping about autism. Being scared of difference, being scared of problems."* (ID 48)	58%
2	**Lack of training and education about autism in the workplace** (e.g., Very few employers, HR officers or other staff have any education or training about autism and how it might impact employees.) *"HR understanding of what autism is, inclusion education for all staff members."* (ID 233)	32%
3	**Lack of support from employers** (e.g., Many employers do not give adequate support or accommodations to their autistic employees.) *"Lack of accommodations in workplaces for autistic people."* (ID 151) *"Lack of ongoing support and empowerment to sustain and retain people once they commence work."* (ID 959)	31%
4	**Workplaces' ableist culture and limited willingness to change.** (e.g., A lot of employers are not willing to make changes to the ways they have always done things.) *"Inability to adapt to change, update knowledge and show compassion to autistic employees."* (ID 753)	26%
5	**Discrimination, stigma, stereotyping, and bullying at work** (e.g., Autistic people are often a target of workplace discrimination or bullying.) "*Discrimination - which is hidden, not overt enough to fight."* (ID 639) *"Co-workers perception of flexibility and supports as preferential treatment increasing potential for bullying."* (ID 1020)	24%
6	**Communication and interaction issues** (e.g., There is a lack of understanding that autistic people may communicate or interact with people differently.) *"Being reprimanded and discouraged for communicating in more comfortable ways i.e. email rather than face-to-face, or needing to 'smile' to be considered friendly."* (ID 842)	21%
7	**A workplace culture dominated by deficit-based models of autism and not acknowledging the autistic employees' strengths** (e.g., Most employers seem to know about the challenges that autistic may bring to the workplace, but know nothing about their strengths. *"Lack of knowledge about the special skills, talents, attributes, thinking, and communication styles people with autism have and can bring to a workplace."* (ID 1440)	15%

8	**Finding a job can be taxing for autistic people** (e.g., Very few accommodations are offered to or made for autistic people which would make the process of getting a job easier for them.) *"The people making the recruitment decisions and then managing staff don't know anything about autism and/or don't communicate with the autistic person to ask what they need to participate in recruitment processes or function in their role."* (ID 159)	13%
9	**A dominant capitalist culture** (e.g., Profits are valued more highly than people.) *"Capitalism. Yeah I know, but a system that at its core values profit ahead of societal good definitely contributes."* (ID 1075)	9%
10=	**Limited job opportunities for autistic people** (e.g., potential employers not being willing to take a chance on employing an autistic person.) *"Attitudes that we will cost money to accommodate so its not viable to employ us."* (ID 1410)	8%
10=	**Workplace environment not accommodating for autistic people's needs** (e.g., The needs of autistic people are often not able to be met in the workplace environment) *"Office layouts, particularly open-plan or shared offices, without individual offices, or quiet places to work. This environment, as well as having to mask / camouflage for extended periods of time, is exhausting to neurodiverse people, and actually prevents me from working effectively."* (ID 1458)	8%
10=	**Limited support available to autistic people in workplace** (e.g., Some employers expect the autistic employee to work out what accommodations they want, rather than working with them to accommodate their needs). *"Placing the burden on people with disabilities to actively set out reasonable adjustments that can be made." (ID 873)*	8%
10=	**Lack of flexible working options** (e.g., Many employers do not realise that accommodating for autistic needs will increase productivity; do not allow flexible working arrangements.) *"Companies believing that flexible working arrangements will decrease productivity or needing to be open during business hours and needing employees to work then." (ID 1051)*	8%
14=	**Lack of support (incl DES problems, services)** *"Disability employment services employ untrained and ignorant people, many will push autistic people into roles they wouldn't succeed in and force them to undergo training with organisations that are unable to provide learning support."* (ID 81) *"Many autistic adults are just thrown onto Jobseeker or The DSP [Disability Support Pension] and left to their own resources, hopefully with a carer to assist. There is no suggestion of actually finding them a job with an authorised employer, nor is there any suggestion of their job provider attending an interview with them, they are literally left to fend for themselves. Carers (if they have any) are then involved in trying to help the person find work."* (ID 915)	6%

14=	**Workplaces not suitable - difficult to meet expectations, not enough sick leave, unstable jobs** *"Unnecessary/unfair expectations about what is expected at work, besides doing the job you are paid to do."* (ID 157) "*Lack of willingness to make changes - actually have people working in different ways/times in a work setting as it 'might not be fair on the average work staff'. Missed the whole point."* (ID 1096)	6%
14=	**Lack of financial support/ incentives for employers, Government funding** "*No financial incentives or penalties for employers to fulfil obligations in providing a safe supportive workplace."* (ID 134) *"Lack of knowledge and awareness. Perceived lack of time and/or funding to implement inclusive processes and procedures and invest in physically accessible workplaces."* (ID 558)	6%
17	**Education and training is lacking for autistic people** *"Lack of education and programs that adequately support the rights of autistic people to have access to employment that is safe and meaningful to them."* (ID 624) *"Difficulty getting post school training in TAFE or other institutions."* (ID 1208)	5%

Question 3: What do you think could prevent or reduce these problems?

Rank	Factors that could prevent or reduce the problems experienced by autistic people in relation to employment and sample quote from responses	% of all respondents who stated this issue
1	**Education and training for employers and staff at workplaces** (e.g., Improving education and training about autism for all staff would improve understanding, awareness and acceptance of autistic employees.) *"Training for employers and people generally around what autism actually is. Social health campaigns around autism, neurodiversity and disability in general may also help."* (ID 882)	36%
2	**Accommodations, mentorship, and supports from employers** (e.g., Making accommodations and providing mentors and/or other required supports to autistic employees will enable them to work to the best of their ability.) *"Accommodations within the workplace to enable autistic people to work to the best of their ability."* (ID 1158)	33%
3	**Realistic representations of autism in social media, showing what employing an autistic person means** (e.g., There needs to be more realistic depictions in the media of autistic people and what it is like to employ an autistic person. This would give potential employers a better understanding of what it might look like for them.) *"Increased promotion of what employing an autistic person looks like and avoid standardised perceptions - i.e., they are great at IT and prefer to work on their own because they don't like making friends."* (ID 690) *"Autistic people being showcased, promoted and presented as role models within their workplaces. Reframing of autistic people being different, not difficult."* (ID 852)	14%
4	**Improved understanding of autistic strengths** (e.g., There needs to be a better understanding of the strengths that autistic people can bring to the workplace.) *"Start valuing people as people and believing that they can be contributing members of society."* (ID 1251) *"Asking people about their strengths and preferences and accommodating those where possible."* (ID 440)	13%
5=	**Training and accommodations for autistic people applying for a job** (e.g., Potential employers need to make adjustments to the process of employing people, so it will be more inclusive.) *"Relook at how we value workers in a society, what is required in a job interview and what is unnecessary. (e.g. If you have typed up a resume and are applying online, you don't need to input your resume into specific boxes, and then upload your resume and a cover letter that doesn't get read. That is so difficult for a neurodivergent person to complete! So many steps."* (ID 935)	11%

5=	**Increased financial support/ incentives for employers, government funding** (e.g., The government should give financial support to employers to employ more autistic people.) *“Financial incentives for private businesses to hire and retain autistic people* e.g., *no payroll tax on autistic employees, along with financial penalties for discriminating against disabled employees which are strong enough to deter and easy to enforce so that they are actually effective.”* (ID 195) *"To help influence societal change enforce quota systems in all government departments to employ people with autism. Allow government to act instead of just talk. Actively advertise and communicate the benefits of employing people with autism and celebrate the unique skills, talents and qualities they bring to a workplace. We're not all good just at IT stuff!”* (ID 1436)	11%
5=	**Improve understanding, awareness and acceptance of autism in the workplace** (e.g., Employers and other staff should have a better understanding and awareness of autism and be more accepting of autistic differences) *“Acceptance of different work styles and preferences, including for sensory regulation.”* (ID 187) *“Increased employer knowledge and understanding of how autism could effect an individual in the workplace and how best to support them with succeeding.”* (ID 372)	11%
5=	**Boost inclusivity culture at workplace.** (e.g., There needs to be more willingness to change and improve attitudes towards including more diverse people) *“A top-down culture change that is precipitated by open communication about differences. Changes to policies and procedures affected by the employee lifecycle. Opening up a channel for employees with neurodiversity (or disability in general) where there is forum for constant communication to senior levels of management. Awareness training for all would be- or already are- managers, regardless of whether their employees have disclosed disability.”* (ID 1415)	11%
9=	**Improve discrimination, stigma, stereotyping and bullying in the workplace** (e.g., There should be a willingness to make changes to workplace procedures and policies to protect autistic people) *“Improve stigma around autism by education (sic) the public. Supports in the workplace available to all” (ID 1411)* *“More stringent policies that businesses must comply to for Neurodiverse people Easier way to report any instances of bias and other negative issues Rewarding businesses for being neurodiverse friendly. Not superficially ND [neurodiverse] friendly.” (ID 417)*	8%
9=	**Develop job readiness programs for autistic people** (e.g., Autistic people need help to prepare for work from organisations and people such as Disability Employment Services, support workers and other programs.) *“Having more readily available access to workplace training that can be geared to a variety of workplace types and sizes.”* (ID 330)	8%
9=	**Listen to the thoughts and ideas that autistic people have** (e.g., Autistic people often know what they want or need, so ask them to share that information) *“Fund autistic led organisations to help autistic workers develop self-advocacy skills.”* (ID 343) *“Include input from autistic staff in designing position descriptions.”* (ID 532)	8%

12=	**Work-place suitability - improve building design/ physical environment to account for sensory needs** *”Consideration given to environments and work practices that are good for all humans - spaces that dampen noise or allow for quieter spaces for de-regulation of emotions.”* (ID 41) *“Building design should incorporate sensory friendly design. This is a universal design aspect that actually could benefit everyone not just Autistic people so should be standard practice.”* (ID 90)	5%
12=	**More/ better access to support** *“Support to prepare for work, find suitable employment prospects, develop application and interview skills, understand customer service, develop social communication skills for the workplace.”* (ID 408) *“Autistic governing body- Someone who knows work rules in and out that can appear on behalf of the autistic person. Anywhere at any time. Is payed by the government.”* (ID 1125)	5%

Question 4: What is working well, or has worked well, in relation to autistic people accessing employment?

Rank	What is working well, or has worked well, in relation to autistic people accessing employment and sample quote from responses	% of all respondents who stated this issue
1	**Flexible workplace arrangements** (e.g., Autistic people work best when they feel supported and their workplace needs are being met; flexibility contributes significantly to that.) *"Giving reasonable accommodations to the work environment to make it more accessible."* (ID 51)	24%
2	**Supportive employers who promote inclusivity** (e.g., Inclusive employers support autistic employees to work the way that suits them best.) *"My first two bosses gave me lots of space to grow my own interests and they also allowed me extra time. They celebrated when I was right and also when I was wrong. I had two great bosses."* (ID 185)	23%
3	**Accommodations at work supporting autistic peoples' sensory needs** (e.g., When autistic sensory needs are met, autistic people feel valued and can work well.) *"Sensory needs met whether it's regular movement breaks, lighting dimmed, work from home so noise and other sensory needs are met."* (ID 75)	22%
4	**Colleagues who embrace inclusivity and neurodiversity** (e.g., When other staff are accepting of neurodiversity, it is easier to feel comfortable at work.) *"People who are understanding and accommodating of differences even if they do not experience those challenges themselves."* (ID 422)	17%
5	**Employment that matches autistic people's interests or strengths** (e.g., Autistic people work exceptionally well when their work tasks match their strengths.) *"If you manage to get a job and it is a role that suits your strengths you do an amazing job."* (ID 88)	12%
6	**Nothing has worked or I do not know** (e.g., For some people, nothing they have tried seems to have worked, or they do not know what is likely to work for them.) *"Nothing has worked well. ASD [autism] is taken advantage of, their technical ability, paid less for working harder, paid less than anyone else, male or female. Taken advantage of their deep and often knowledge especially their special interests."* (ID 469) *"I have no idea. I've not managed to keep one job for longer than a few years."* (ID 436)	11%
7	**Educating employers and their staff about autism** (e.g., Having education sessions about autism and neurodiversity can help staff to be more accepting and understanding.) *"Workplace education campaigns focused on neurodivergent conditions (I lead this recently at my workplace with great success)."* (ID 246)	7%

8	**Workplace routines, consistency, and clear instructions** (e.g., Having regular routines and clear instructions helps autistic people to be competent and confident at work.) *“Explicit workplace feedback, with constructive information to help them know how to improve.”* (ID 1079)	6%
9=	**Supportive and autism-friendly recruitment process** (e.g., Changing the recruitment process to make it more inclusive can help autistic people to gain employment.) *“A great example is Reframing Autism's options when interviewing for a job. For example, do you want to answer questions in writing, in a recording or in a telephone interview? This is a really good practice, I think”* (ID 479)	5%
9=	**Supported employment programs** (e.g., Supported employment can be a meaningful alternative for those who may find employment on the open market to be unsuitable.) *“Supported employment is a viable option for some autistic people like my son - his provider [name of a service provider] in WA is amazing - they support his mental health challenges every day and expand his work capacity. Lots of disability advocates criticise supported employment but it does have a place for some people.”* (ID 859)	5%
9=	**Autism-specific employment or internship opportunities** (e.g., Positions that are created specifically for autistic people give them opportunities to learn and show employers their skills and strengths.) *“Specialist internships for autistic people (a long work trial where they get paid, but are also learning).”* (ID 190)	5%
9=	**Being self-employed or work in a family business** (e.g., Self-employment or family businesses give autistic people opportunities to utilise their strengths in a workplace of their own, or with people who know them well, who will support them to succeed.) *“Supporting entrepreneurship and self-employment for autistic people. I was self-employed for much of my working career so I could design my working schedule to suit.”* (ID 190)	5%

Appendix G-2: Umbrella review search terms

Databases Searched

(title, abstract, and key words)

- CINAHL
- Cochrane
- EMBASE
- ERIC
- Emerald
- Medline
- PsycINFO
- Pubmed
- Scopus
- Web of Science
- Google scholar

Search Terms

The following search terms were used to identify relevant articles

Autism	Review	Employment
autis* OR ASD OR ASC OR Asperger* OR “pervasive developmental disorder*” OR PDD	“systematic review*” OR “scoping review*” OR “narrative review*” OR “systematic literature review*” OR “systematic quantitative literature review*” OR “evidence synthes*” OR meta-analy* OR meta-regression*	Employ*t OR job OR work* OR vocation* OR hiring OR hire* OR occupation

Inclusion and exclusion criteria

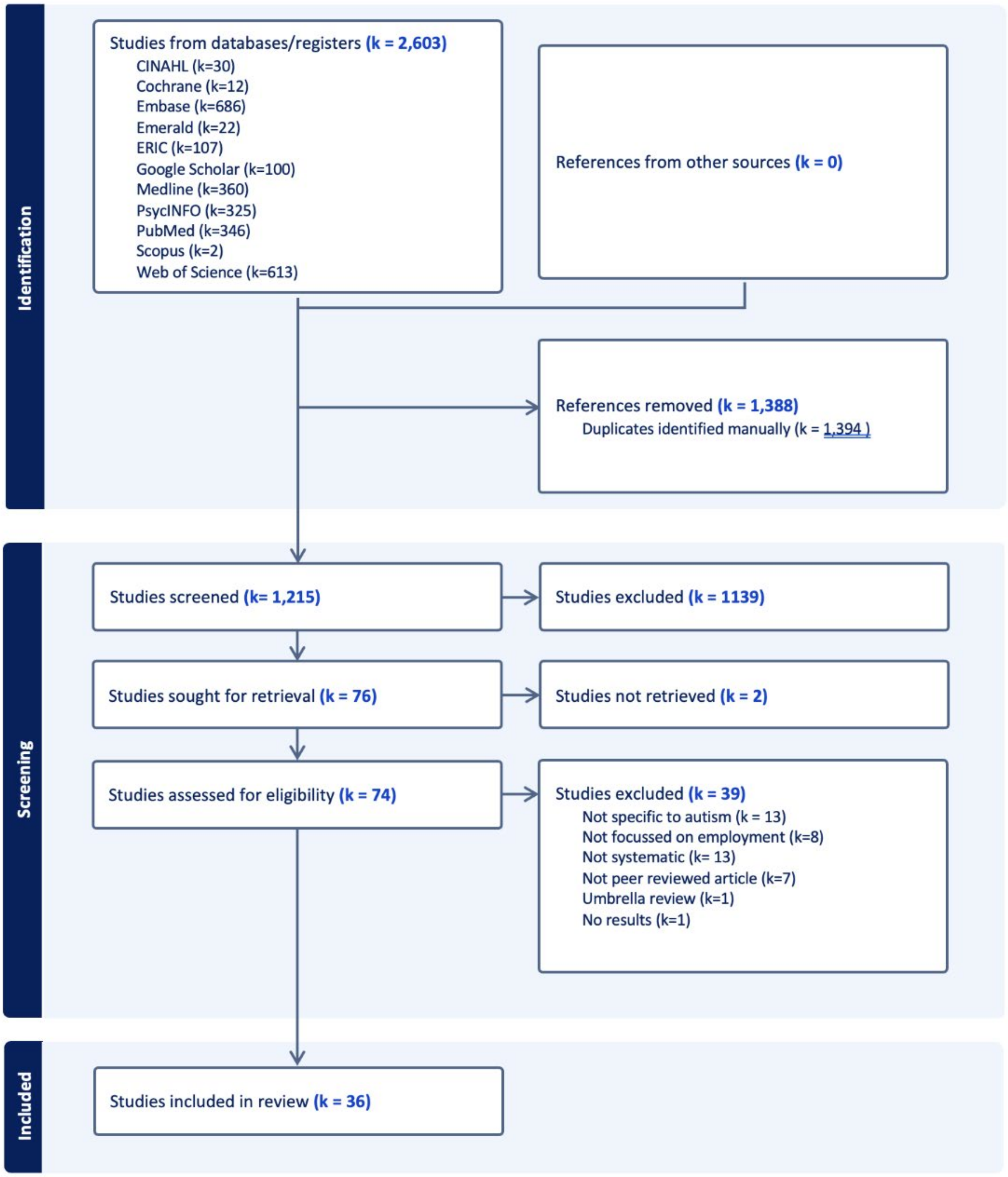
General **inclusion criteria** are below. The study must meet all of these to be included.

1. The article reports on a review of the literature that was undertaken systematically. A review will be considered "systematic" if it: (1) includes a clear statement of the purpose of the review; (2) describes the search strategy (i.e., key search terms, multiple relevant databases, specification of search limits); (3) indicates the criteria used to select studies for inclusion; and (4) presents all findings relevant to the main purpose of the review
2. The article must focus on autistic (human) participants, or if it is part of a review on broader conditions, the articles on autistic human participants must be reported on separately
3. The article must report on articles relating to an aspect of employment
4. The article must be published in a peer-reviewed journal

The **exclusion** criteria are listed below. A study only needs to meet one of these criteria to be excluded:

1. Articles or reviews that do not meet the criteria to be considered "systematic" (for example (for example, narrative and unstructured reviews, primary studies, opinions, commentaries, letter, book chapters, conference abstracts or editorials)
2. Umbrella reviews, rapid reviews, or "reviews of reviews"
3. Reviews that do not focus on autism, do not report autistic participant studies separately or do not report on human studies.

Appendix G-3: PRISMA diagram



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Appendix H: Housing design

Appendix H-1: Content analysis categories

Question 1: What are three problems that autistic people experience in relation to housing?

Rank	Problems experienced by autistic people in relation to the housing and sample quote from responses	% of all respondents who stated this issue
1	**Access to affordable living accommodations** (e.g., low availability of public/social housing; complex housing pathway; high rental costs; inadequate government assistance for housing) *"Lack of support to get and sustain housing NDIS is not appropriately supporting or funding this."* (ID 105)	48%
2	**Timely access to public housing as currently there is a long wait list** (e.g., shortage of social/public housing; results in living with family or trying to get private rentals in a competitive rental market) *"It takes a long time to get public housing and they are often dependent on family or rental market… [there is] huge shortage in current rentals and public housing, [and] waitlist is huge."* (ID 705)	21%
3	**Ability to cover the costs related to housing** (e.g., unemployment or under-employment of autistic people affects ability to afford housing within budget; high costs of living) *"Cost vs income - which may be lower due to not being able to work full time or struggling to find work. Poor work prospects leading to low incomes. Lack of access to employment opportunities reduces income and makes housing unaffordable"* (ID 48)	19%
4	**Suitability of accommodation to autistic needs** (e.g., interpersonal challenges with shared housing; limited consideration for the best fit housing options for autistic people) *"Relationship difficulties in share housing situations, including conflict arising from the person's particular sensory, privacy & communication needs. Sometimes it is better that they live alone with a pet, being able to access housing with (a) pet, rather than being told they cannot."* (ID 168) *"Lack of suitable options for those who can't live in group settings or with family - need bespoke options" (ID 790)*	18%
5	**Ability to choose from a variety of housing options** (e.g., lack of a range in living options) *"Lack of understanding and putting those who don't want to live in a group home no other option but to do so" (ID 409)* *"Lack of consideration of what an individual might require and the different types of housing needed for different groups of people on the spectrum" (ID 416)*	17%

6	**Support with navigating the renting process and its related communication and interactions** (e.g., rental process is complex and hard to understand; lack of support to assist autistic people with understanding rental processes including rental contracts) *“The behaviour of real estate agents who manage rental properties. They are often the sort of people who try to take advantage, and Autistic people are often very vulnerable in that situation. The states that have clear rules about rental rights and responsibilities make this situation easier to deal with, but it's still a huge problem. Oh! The biggest, maybe! Rental contract instability! Rents seem to go up every time the contract renews, which is usually every six months, which often means you have to move out. It's horrendous. There is no certainty, so much fear and stress. I believe some people negotiate or some such, but that would involve dealing with shady real estate agents and reading their social cues (e.g., are they being serious or should I push here?) - a process that can be beyond the skills of many Autistic people. Getting a rental or home loan is extremely hard because of my lack of communication skills and my social anxiety. Getting bad references if you screw up when you can't cope with work or life. Real Estates often perceive you as mentally challenged and won't rent to you.”* (ID 479)	14%
7=	**Feeling safe when living independently** (e.g., lack of robust housing or housing that is physically and psychologically suitable for the needs of autistic people; areas where public/social housing is available may be dangerous) *“Housing in dept housing estates can be very confronting, even dangerous to autistic people due to lots of social / drug and alcohol abuse fueling violence that gets targeted to the most vulnerable. Safe housing (by safe I mean safe to that person and their nervous system; sensory wise, accessibility wise, close to their connections etc.) is pretty much inaccessible to us.”* (ID 300)	13%
7=	**Receiving financial support from the NDIS** (e.g., inadequate funding from NDIS to support housing needs; lack of accountability within government agencies related to housing support for autistic people) *“Lack of accountability from State Governments to provide especially for those with severe and profound autism buck passing between state and federal governments. NDIS should not artificially limit amount of SDA [Specialist Disability Accommodation] that can be provided. Lack of housing for supported independent living. The NDIS needs to provide accommodation for people like me in this matter. I am currently living in the private rental market in a very small duplex and paying high rent. I am concerned about this rent increasing and the cost of living. I also am concerned about social isolation and lack of both awareness and support.”* (ID 775)	13%
9	**Suitability of the accommodation structure** (e.g., lack of housing designed with consideration for sensory sensitivities and spatial needs of autistic people; autistic people unable to make modification to rental houses to meet their needs) *Autistic renters are unable to alter their homes to meet Autism specific needs such as sensory needs. Small lot sizes make neighbours noisier, which I struggle to cope with and there is a lack of privacy from neighbours. Noise and other sensory-related issues”* (ID 290)	12%
10=	**Lack of support with the rental process and with understanding a tenant’s rights, having pets, routine inspections** (e.g., lack of support to assist autistic people in understanding their rights, responsibilities, and expectations related to rentals)	11%

	“Landlords constantly showing up cuz they don't trust you cuz you're different, long contracts we usually don't get to read through until after the fact, having to be social to even get a place” (ID 202)	
10=	**Living independently** (e.g., lack of independent living skills among autistic people who desire to live alone or outside the family home) *“Not having the life skills to live on their own. I have a son who would love to move out eventually but would struggle immensely house sharing with people he doesn't know. He struggles to clean, cook, maintain a yard and access emergency services”* (ID 594)	11%
12=	**Discrimination and social issues** “*Real estates often perceive you as mentally challenged and won't rent to you. Or they think you don't deserve to be on a Disability Pension. See us a damaging or destructive person. The whole country is having housing issues but we get put further back on the list than others.*” (ID 793) *“Underestimation of their capability to live alone or hold a job.*” (ID 1142)	9%
12=	**Support for disabled owner/ occupiers and tenants** *“Gaps in housing supports - people with autism are not eligible for supported independent living but almost never gain success in the open rental market meaning they are forced to stay at home with parents*.” (ID 247) *“Usually living with parents or care-givers, not even think of future housing issue. Don't have capacity to move out or to live independently Don't know about housing services, no support to access it.”* (ID 667)	9%
12=	**Support staff and government agencies** *"Lack of funding for training and support for those caring for our autistic people in housing”* (ID 579) *“No specifically autistically trained Housing staff”*. (ID 153)	9%
15=	**Homelessness** *“We are seeing a high level of homelessness in our ASD clients due to the inability to maintain employment and lack of social skills. Many parents of our undiagnosed ASD clients are also undiagnosed as they have lived in the cycle of poverty themselves and were unable to access assessment due to the cost barrier*.” (ID 1238) *“The Autistic community has higher rates of people experiencing homelessness and living in inadequate housing (e.g., houses that need repairs). Autistic people are often mistreated, and their needs are not met, in communal disability homes.”* (ID 290)	5%
15=	**Functional skills** *“That they are able to fill out paperwork correctly. That owners look at an autism in a bad light. That a person with autism finds the whole process difficult because it's not shown to us how it is and every thing is always changing on how to do things. Eg online forms*.” (ID 858) *“Challenges living with non-autistic people in shared housing. Not having the life skills for live on their own. Naive about money lenders and predatory lenders for home loans/furnishing/insurance etc”* (ID 446)	5%

Question 2: What do you think is causing these problems?

Rank	Factors causing the problems experienced by autistic people in relation to housing and sample quote from responses	% of all respondents who stated this issue
1	**Lack of affordable housing options** (e.g., lack of available public/social housing; high costs of rentals and high costs of living) *"The private rental market is not affordable to most people on DSP and people with ASD have support needs that normally exceed what is suitable for mainstream housing options."* (ID 60)	30%
2	**Lack of understanding and awareness about autism** (e.g., Lack of understanding of the needs and experiences of autistic people in the public, among health workers, housing organisations and the NDIA) *"Social workers, employers, housing organisations and real estates do not understand how ASD symptoms can present and they do not fully understand the impact this has on an Autistic individual."* (ID 616)	29%
3	**Lack of suitable housing options** (e.g., lack of appropriate social housing; lack of consideration and accommodation for the needs of autistic people; difficulties with interpersonal relationships) *"No social housing. Being autistic makes living with others very difficult."* (ID 206) *"Group residential settings not giving autistic adults and young people voice and agency."* (ID 696)	26%
4	**Limited government housing** *(*e.g., shortage of social/public housing; lack of focus on housing as a priority) *"Lack of public housing for people at high risk."* (ID 24) "*Lack of supply of building materials, lack of insight by the government to increase housing. Limited options to support people impacted by these decisions by the government, NGO's."* (ID 705)	23%
5	**Limited resources and funding** (e.g., lack of funding for disability housing; lack of appropriate and targeted government funding for autistic people) (*"Lack of funding for disability homes."* (ID 290)	20%
6	**Support from government (incl NDIS and DSP, rent assistance)** (e.g., inadequate funding support for housing needs; limited planning for social housing, DSP [Disability Support Pension], and JobSeeker payment inadequate support for autistic people) *"Lack of Government support or housing options for autistic people which results in them heavily relying on family. Lack of money to look for housing independently."* (ID 47)	19%
7	**Employment, income and work capacity issues**	15%

	(e.g., limited working capacity and income potential for autistic people; high unemployment or under-employment of autistic people) *"Many autistic people have significant permanently limited work capacity but would not qualify for the Disability Support Pension due to unfair criteria. Money - holding down a job while being autistic can be hard."* (ID 81)	
8	**Support with systems and processes** (e.g., poorly integrated government systems; long processes to access support and lack of support to navigate government systems) *"The SDA process is too long and difficult to manage. It took three years for us to go through with our young person, and $11,000 in assessments. Inability to Advocate for themselves and/or their families or unable to get access to an advocate support service. I can no longer access the NDIS because the amount of work involved to gain access to the support I need has become too overwhelming for me to comprehend."* (ID 91)	10%
9	**Stigma and discrimination** (e.g., lack of awareness among stakeholders about the discrimination autistic people experience; limited support available unless perceived as 'high needs;' real estate agents will not rent to autistic people if perceive them as mentally challenged) *"Shame and stigma for the person experiencing difficulties. People automatically assuming the worst about people who are different."* (ID 381)	9%
10=	**Renting and its related communications are complex** (e.g., lack of understanding among autistic people about the rental process, rules and social and non-verbal cues that guide negotiations when renting) *"The rental system. It's horrendous. Horrible for everyone, but particularly for the more vulnerable, such as Autistic people... Rents seem to go up every time the contract renews, which is usually every six months, which often means you have to move out. It's horrendous. There is no certainty, so much fear and stress. I believe some people negotiate or some such, but that would involve dealing with shady real estate agents and reading their social cues (e.g., are they being serious or should I push here?) - a process that can be beyond the skills of many Autistic people." (ID 479).*	7%
10=	**Lack of support with activities related to housing** (e.g., lack of support to help autistic people with housing processes such as applying for rental or getting home loans; poor understanding among autistic people of how to run a household) *"No supports available unless perceived to be 'high needs'. Disability was mostly associated with physical access to housing. Autistic needs relate closer to normal housing but with some executive functioning assistance - hence ILO. The environment and each autistic personality may be triggers to other autistic people"* (ID 381)	7%
10=	**Unknowledgeable support staff** (e.g., support staff lack sufficient education; understanding of autism and ill-equipped to help advocate for autistic people) *"Inability to Advocate for themselves and/or their families or unable to get access to an advocate support service." (ID 1351)* *"Ignorant staff and not qualified."* (ID 597)	7%

10=	**Government policies are a barrier** (e.g., lack of government investment or interventions to improve access to public/social housing; lack of policies that support autistic people with housing access) *“Both commonwealth and state gov not investing sufficiently in programs that could lead to more effective housing solutions.”* (ID 1227)	7%
10=	**There is limited understanding about the abilities and capacity of autistic people** (e.g., lack of understanding among decision-makers about the needs and capacity of autistic people to guide funding allocations and policy) *“People who make decisions have very little knowledge of the real impact a severe ASD diagnosis has on a person and family and they restrict access to services and funding that is desperately required to keep the person with ASD safe.” (ID 835)*	7%
14	**NDIS requirements** *The few people illegally accessing NDIS make it even harder and more overwhelming for those of us who actually NEED the NDIS. I can no longer access the NDIS because the amount of work involved to gain access to the support I need has become too overwhelming for me to comprehend.* (ID 162) *Enforcement of absurd or nonsensical requirement which interferes with other productive processes.* (ID 178)	6%
15	**Lack of information/ difficulty accessing info** *“Their parents or care givers don't know about housing services or don't have a long term planning.”* (ID 667) *“Forms and processes for rental or buying a property are designed for neurotypicals.”* (ID 837)	5%
16	**Criteria for services/ assistance** *“Many autistic people have significant permanently limited work capacity but would not qualify for the Disability Support Pension due to unfair criteria. Autistic people require significant environments to be successful and healthy but these needs are now too unaffordable to be met.*” (ID 81) *“Not recognising the amount of unidentified people in community. No supports available unless perceived to be ‘high needs’.”* (ID 381)	5%
17	**Lack of autistic input in decision making** *“Assumptions. No input from the person who is Autistic or neurodiverse and decide for them not with them.”* (ID 369) *“Cost effectiveness valued over dignity and choice in living in preferred space. Differences in values towards chores and hygiene compounded by lack of practice in independence*.” (ID 492)	5%

Question 3: What do you think could prevent or reduce these problems?

Rank	Factors that could prevent or reduce the problems experienced by autistic people in relation to housing and sample quote from responses	% of all respondents who stated this issue
1	**More housing options for autistic people (incl. location, rent/own/build, structure, singles/ families, supported accommodation)** (e.g., provide more public/social housing; more supported accommodations specific to the needs of autistic people) *"Having more housing, options for people mid-level support needs under NDIS. Actually asking autistic people what will work for them and building services based on needs."* (ID 105)	25%
2	**Education to increase acceptance and understanding about autism** (e.g., provide autism training for housing staff, architects, families, people in the education system about the sensory and spatial needs of autistic people) *"It starts with reforming the school system. With reforming and reframing societies perception of Autistic people. Make schools & employers more autism-friendly."* (ID 1131)	22%
3	**More flexible financial support opportunities** (e.g., NDIS provide flexibility in guidelines and funding for home modifications; flexibility in funding different housing options) *"Funding support to cover costs of making accommodation accessible in different ways to encourage a patchwork of accessibility. Better access to NDIS support for independent living."* (ID 77)	19%
4	**Access to autism-specific support** (e.g., make schools and employers more autism friendly; increase housing support; mandate housing as a human right) *"More autistic training for Housing staff, along with more specialised supports, options and assistance available for autistic clients. Housing linking and partnering with more autistic based specialised supports. Supports to assist with securing and sustaining private housing. Financial 'translators' that autistic people can access for large life changing commitments and decisions. Contracts/rental agreements to be in plain language and having a support person to explain."* (ID 446)	18%
5	**More affordable and appropriate public housing** (e.g., increase social housing; stricter regulations on pricing for community housing providers; better; more rules and regulations regarding the maintenance of rental properties) *"Need a lot more investment in affordable housing. Cheaper and safer housing options for people at the edges of society."* (ID 935)	17%

6	**More housing options for autistic people (incl. for singles/ families/ shared, supported accommodation)** (e.g. increase funding for single occupancy arrangements; improve selection processes for shared housing to reduce interpersonal conflicts; provide more need/preference-based housing options) *“More individual supports and services for those who wish to live alone. More individual flats or villas for individual accommodation. More options of smaller one bedroom houses. Develop concepts of ILO much more with perhaps some innovative arrangements”* (ID 553)	14%
7	**More accessible financial assistance** (e.g., better pensions to account for cost of living and housing expenses; provide rent assistance; flexibility in requirements for Disability Support Pension) *“Loosen the restrictive requirements for the disability support pension so autistic people can access appropriate financial assistance. Many people do not get funding or the Disability Support Pension, even though they have autism because they are considered ‘too high functioning’, despite the fact that they may have extreme difficulty getting and keeping a job. Make DSP more accessible for autistic people”* (ID 81)	13%
8=	**More autism-specific and autism-friendly accommodation** (e.g., recognise unsuitable housing; increase autism specific housing; provide specialised trained staff for supported living) *“Create housing and supported living opportunities for neurodivergent people who do not require carers but do require consultative mentorship. We need Autism specific disability homes staffed by specially trained staff. Accommodation specifically for adults on the autism spectrum with privacy issues and other areas being addressed.”* (ID 247)	11%
8=	**Improved and manageable renting system** *(e.g., improve government policies and regulations that cap the prices of rentals; regulations that allow autistic people to make some modifications to rental properties)* *“The rental market needs regulations which allow Autistic renters to make subsidised changes to their homes (e.g., in types of heating/cooling and paint colours). The government needs to put renters first. Capping rent so it can't go up every six months, making it harder for landlords to send their minions (i.e. the real estate agents) out to harass their tenants.”* (ID 290)	11%
8=	**Improved access to public housing, reducing wait times** (e.g., increase funding of social housing; provide more homelessness support; have special listings for autistic people) *“Reduce the waiting lists for public housing. A special listing for people with autism.”* (ID 528)	11%
11	**Support to obtain housing** *“Better advertising of online applications. More options of smaller one bedroom houses. More support with legal processes- eg buying a house” (ID 553)* *“Advocacy and services to support independent living processes.”* (ID 860)	10%

12	**Acceptance and understanding - reduced discrimination, improved acceptance** *“Improved disability discrimination laws and access to make complaints. Financial assistance to Autistic individuals who can work as well as those who can't.”* (ID 51) *“Acknowledgement of the value of diversity and neurodiversity; acknowledgement of the different ways that different people contribute to society”* (ID 955)	9%
13=	**Support - social and community support** *“More autistic run support programs for autistic individuals. Financial 'translators' that autistic people can access for large life changing commitments and decisions.”* (ID 446) *“Community spaces that have supported living, eg. supported living estates where flats and units are available for independent living with supports near by.”* (ID 1282)	8%
13=	**Housing - change criteria for support to include a wider range of autistic people** *“Having more housing, options for people mid-level support needs under NDIS, not a simple yes or no eligibility on criteria that is not made public. Housing put aside, especially for people with disabilities. People with disabilities need priority access to public housing. There also needs to be more disability-specific housing and this needs to be available to people with lower needs as well, such as people with ASD who only need a few hours per day as far as assistance.”* (ID 60) *“A fairer access system, increased accountability on service providers to be trained, qualified and professional.”* (ID 1095)	8%
15	**Accessibility - less complex systems and processes** *“Make it easy for family-centred support models within the NDIS. Where BSPs [Behaviour Support Practitioners] and Q&S [Quality and Safeguards]* Commission *are in play there needs to be easy registration options or other more suitable arrangements.”* (ID 790)	6%
16	**Support from schools and education** *Resources/ training on how to fix simple problems - e.g. purchasing a suitable lightbulb and replacing a light, replacing tap washers etc). Support with funding - e.g budgeting/ pension/ suitable job* (ID 1527)	5%

Question 4: What is working well, or has worked well, in relation to autistic people in relation to housing?

Rank	Factors that are working well, or have worked well, in relation to autistic people accessing housing and sample quote from responses	% of all respondents who stated this issue
1	**Nothing is working well/has worked well** (e.g., unable to identify any aspect of housing that is working well; feeling unsupported when trying to meet housing needs) *"Nothing atm as we won't let our foster son move into the areas that are offered for his own safety. It's all on me. No (suitable) help (yet). Nothing much. Families have to constantly fight for services to be done competently and are always raising concerns of neglect from staff not following care plans."* (ID 504)	33%
2	**When there is NDIS support** (e.g., NDIS support for those who qualify for supported independent living; NDIS housing support services) *"NDIS providing supports for daily living activities."* (ID 1499)	22%
3=	**When autistic people live with their family/carer** (e.g., living with family; having family that make accommodations for sensory and spatial needs) *"Most autistic adults I know have struggled with housing and still live with their parents. Living with families or siblings. The ability to stay at home with family for longer has benefited some with ASD."* (ID 1091)	11%
3=	**When autistic people are supported with independent living** (e.g., able to live alone with support; low density social housing options that allows for more independence) *"Supported independent living is great. Having support to help look after house."* (ID 195)	11%
3=	**When there are existing support networks (including family)** (e.g., having supportive family that can assist financial or with navigating housing processes; having compatible housemates who support each other) *"People such as parents joining together to purchase properties for their children. With strong support from my husband who has ADHD but not autistic, we were able to buy our first home together - his mother also supported us to make our first deposit to crack into the housing market. Without that, we wouldn't be home owners now."* (ID 1251)	11%
6	**When the system is based on individual needs** (e.g., funding that is provided based on specific needs; self-advocacy important to access tailored housing support; housing that is suitable based on individual needs and preferences) *"Flexible funding for flexible needs. We moved to a farm to support our daughter so that we could afford a big enough house that she could have her own bathroom and decent sized room to retreat. The housing solution has made a big difference but it has imposed a long commute to town for our family."* (ID 1199)	9%

7=	**When autistic people live with other neurodivergent people** (e.g., better compatibility when living with other neurodivergent people; mutual understanding and more respect) *"Living with other neurodivergent people. Housing with others whom they are compatible with not just all disability (not segregating)."* (ID 1227)	8%
7=	**When there is financial support for housing and independent living** (e.g., availability of financial assistance such as rent assistance but increased funding for housing is needed) *"RENT ASSISTANCE IS GOOD BUT NOT ENOUGH."* (ID 1199)	8%
9=	**When there is a choice for varied types of accommodation that are safe** (e.g., having a choice in housing option; housing options that are safe from violence and interpersonal conflict) *"I like being independent and living on my own without random people showing up unannounced so being in my own peace is definitely a plus. Low density social housing options that allow for independence, tenancy sustainment and quality of life."* (ID 226)	7%
9=	**When there are supports available for shared accommodation** (e.g., low density social housing; adapted housing with access to support as needed) *"Disability housing with Supports in place."* (ID 1227)	7%
9=	**When there are autism friendly accommodations available** (e.g., having people with similar interest and lifestyles; accommodations that are simple and easy to navigate) "*Special housing/complex for disabled people. From lived experience with a family member I know that the Autistic person is happier, they feel safe, they have something of their own, and something to be proud of. They have their own privacy, and space. Their mental health stabilises. They feel like everyone else."* (ID 1217)	7%

Appendix H-2: Umbrella review search terms

Databases Searched

(title, abstract, and key words)

- Cochrane
- EMBASE
- Emerald
- Eric ProQuest
- Google Scholar
- Medline
- PsycInfo
- PubMed
- Scopus
- Web of Science

Search Terms

The following search terms were used to identify relevant articles

Autism	Review	Housing
autis* OR ASD OR ASC OR Asperger* OR “pervasive developmental disorder*” OR PDD	“systematic review*” OR “scoping review*” OR “narrative review*” OR “systematic literature review*” OR “systematic quantitative literature review*” OR “evidence synthes*” OR meta-analy* OR meta-regression*	"built design" OR "built environment*" OR architect* OR "interior design" OR "sensory design" OR "inclusive design" OR "universal design" OR "building design" OR "human centered design" OR "human centred design" OR "urban design" OR "environment design" OR "facility design" OR "home modification*" *Note: only articles relevant to housing (explicitly or because they are general) should be included.*

Inclusion and exclusion criteria

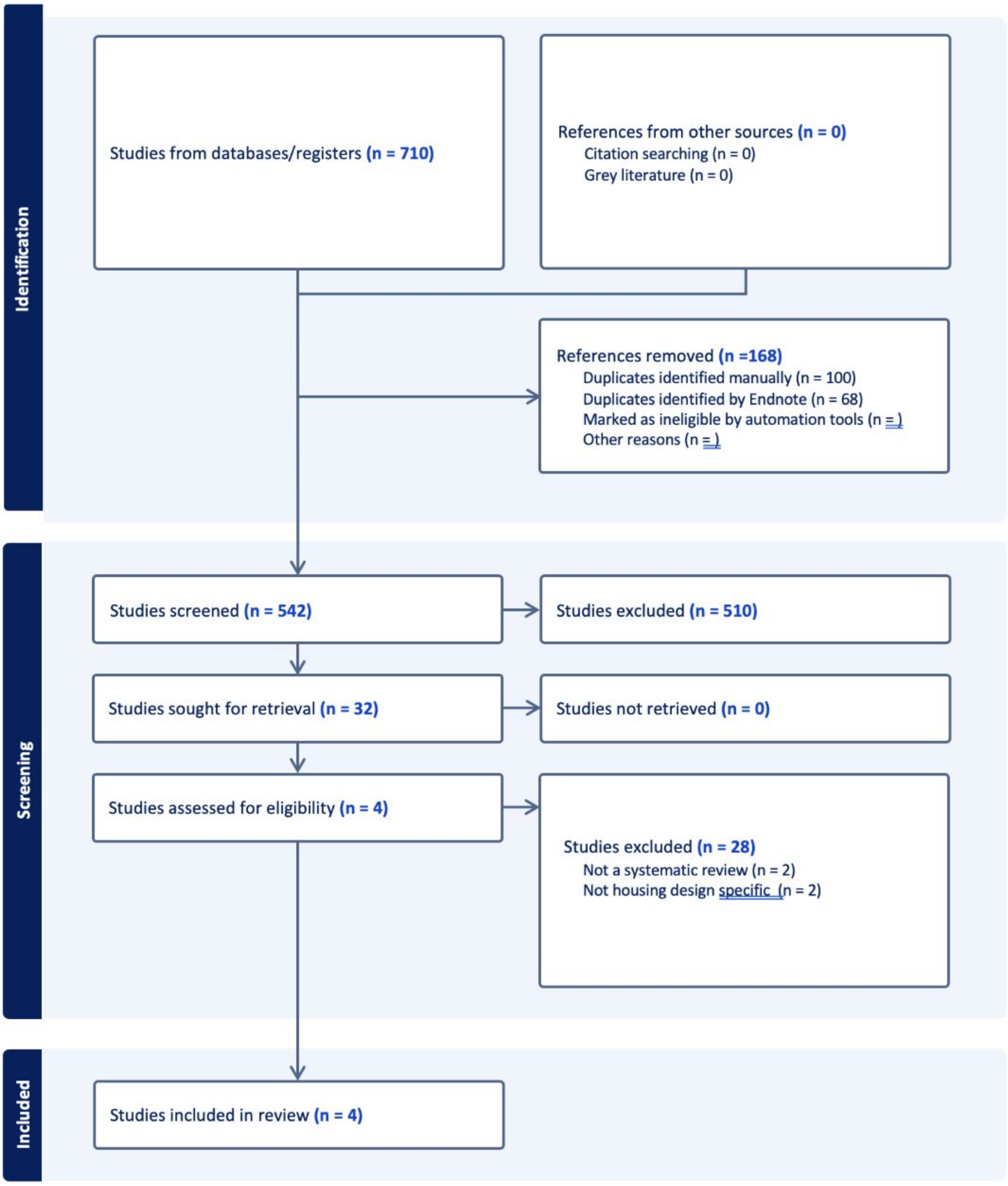
General **inclusion** criteria are below. The study must meet all of these to be included.

1. The article reports on a review of the literature that was undertaken systematically. A review will be considered “systematic” if it: (1) includes a clear statement of the purpose of the review; (2) describes the search strategy (i.e., key search terms, multiple relevant databases, specification of search limits); (3) indicates the criteria used to select studies for inclusion; and (4) presents all findings relevant to the main purpose of the review.
2. The article must focus on autistic (human) participants, or if it is part of a review on broader conditions, the articles on autistic human participants must be reported on separately.
3. The article must report on articles relating to an aspect of employment
4. The article must be published in a peer-reviewed journal

The **exclusion** criteria are listed below. A study only needs to meet one of these criteria to be excluded:

1. Articles or reviews that do not meet the criteria to be considered “systematic” (for example (for example, narrative and unstructured reviews, primary studies, opinions, commentaries, letter, book chapters, conference abstracts or editorials)
2. Umbrella reviews, rapid reviews, or “reviews of reviews”
3. Reviews that do not focus on autism, do not report autistic participant studies separately or do not report on human studies

Appendix H-3: PRISMA diagram



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Appendix H-5: Independent living umbrella review

Umbrella review search terms

Databases searched

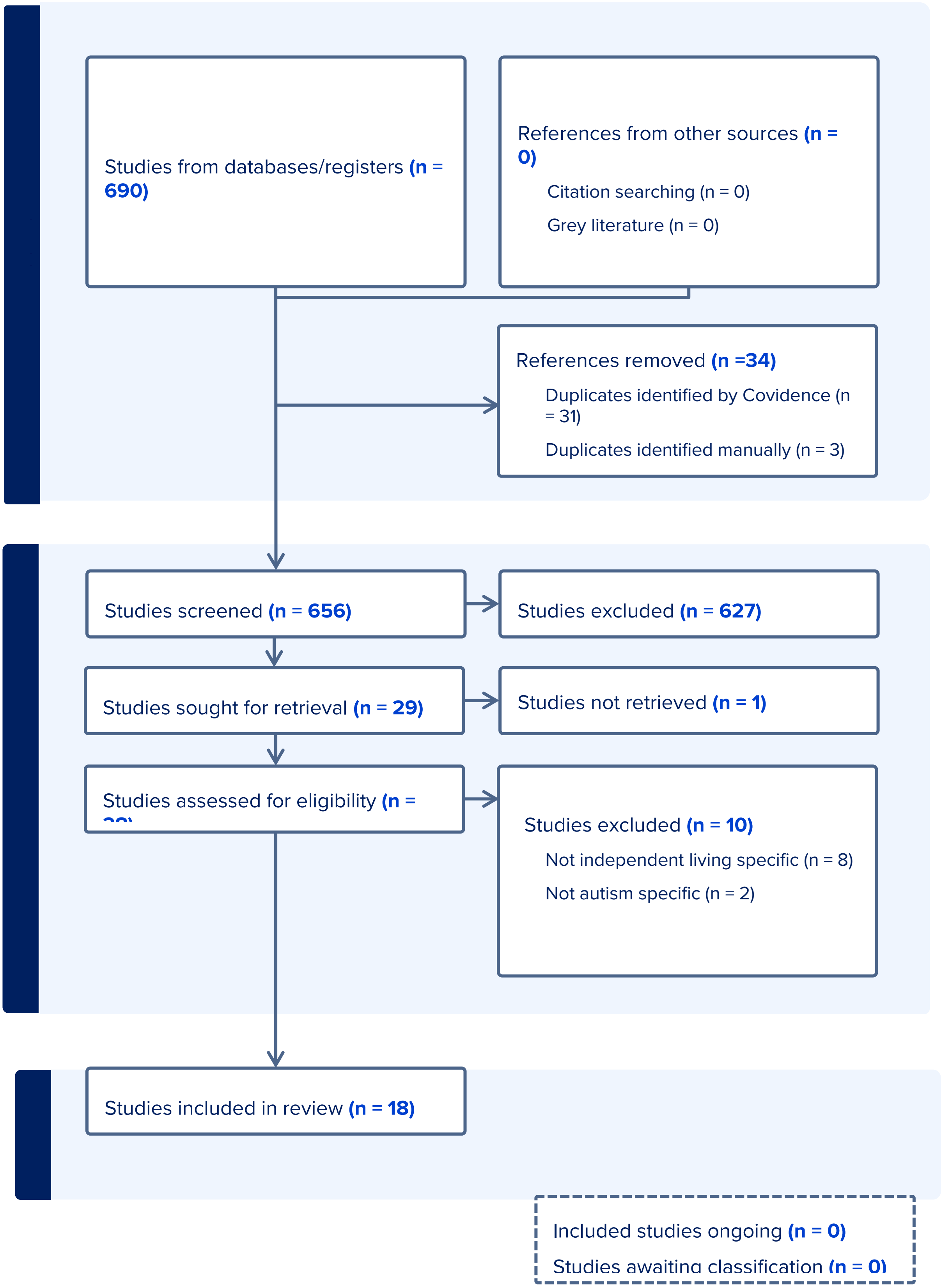
The following databases (title, abstract, keywords) were searched:

- Cochrane
- EMBASE
- ERIC
- Emerald
- Medline
- PsycINFO
- PubMed
- Scopus
- Web of Science
- Google scholar

Search terms

Autism	Review	Housing
autis* or ASD or ASC or Asperger* or "pervasive developmental disorder*" or PDD	"systematic review*" or "scoping review*" or "narrative review*" or "systematic literature review*" or "systematic quantitative literature review*" or "evidence synthes*" or meta-analy* or meta-regression	"Independen* living" OR "Autonomous living" OR "Emancipated living" OR "Separate living" OR "self-sufficient living" OR "indpenden* skill" OR "functional living skill*" OR "domestic skill*" OR "indepenten* skill" OR "life skill*" OR "practical skill*" OR "daily living skill*" OR "activit* of daily living" OR ADL OR self$care OR self$management OR "daily living" OR "daily skill" *Note: only articles relevant to independent living (explicitly or because they are general) were included.*

PRISMA Diagram



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Appendix I: Justice

Appendix I-1: Content analysis categories

Question 1: What are three problems that autistic people experience when accessing, or trying to access, the justice system?

Rank	Problem experienced by autistic people in relation to the justice system and sample quote from responses	% of all respondents who stated this issue
1	**Poor understanding or knowledge of autism and how it presents in different people or contexts** (e.g., specific presentations of autism; and variability in autism profiles, are not understood). "*Professionals in the justice sector having extremely inaccurate ideas about what autism is and how autistic people might function or present in a given context.*" (ID 195) *"Appalling understanding in fact (I am a Dr/GP working in justice health) in that even the forensic psych have little awareness."* (ID 448)	39%
2	**Justice systems or settings (including physical or sensory settings) not supportive for autistic people, sometimes leading to an inability to function or self-regulate** (e.g., justice system contexts like courtrooms are overwhelming on a sensory level; processing and responding to complex information under stress is very difficult for autistic people). "*Autistic victims of crime may have more difficulty describing their experiences to police due to their sensory/social needs not being accommodated.*" (ID 290) *"The rigid structure of the justice system often does not accommodate the needs of an autistic person. They often need a lot of support to stay involved. The drawn out process of a judicial case can be very traumatic for an autistic person, to the point that they will not continue to participate."* (ID 1511)	24%
3	**Characteristics of autism or autistic behaviour (including meltdown, shutdown) misinterpreted or treated as criminal issue** (e.g., minimal eye contact viewed as sign of guilt) "*Meltdowns perceived as defiance and aggression.*" (ID 381) *"My brother used to have a lot of issues with the local police because they didn't understand his behaviours were the result of autist meltdowns."* (ID 935)	22%
4	**Adjustments or accommodations not offered or system not taking into account needs of autistic people** (e.g., lack of access to advocates experienced in supporting needs of autistic people; lack of support during police interviews; lack of clearly communicated information). *"Lack of support to provide us with legal info, legal advice and support through am [sic] end to end legal process."* (ID 1085) *"Lack of access to independent advocates who are experienced with the support needs of autistic people."* (ID 1159)	22%

5	**Autistic language and communication styles or preferences are not accounted for or are misinterpreted** (e.g., autistic people’s communication style/needs not respected or heard). “*Police and courts not being able to talk at their level of understanding and mistaking not understanding questions asked as lying.”* (ID 528) *“Not being heard or understood by law enforcement and the justice system.”* (ID 1004)	20%
6	**Autistic people feeling scared of, dismissed by, or experiencing discrimination from those in justice system** (e.g., being treated as having less rights than non-autistic people; not getting a fair say/fair defence). *“The fear that professionals instil into people with Autism.”* (ID 1303) *“Rights and interests are not addressed or even recognised.”* (ID 1436)	18%
7	**Autistic people may not understand laws, legal or justice system** (E.g., autistic people may not understand legal systems/processes; may not understand, or may have a different perspective of, what they have done). *“Not really knowing what [it’s] all about. others thinking the person with autism does understand [what’s] happening when they engage with justice system when they do not or at least not fully.”* (ID 1093) *“They could be misled by the police into a false confession because they are easily led, want to please and may believe it if the police inform them they do not need a lawyer.”* (ID 1172)	12%
8	**Increased risk of entering criminal justice system including through manipulation, coercion, or not fully understanding the implications of an act** (e.g., autistic people’s trust/naivety may mean they do not recognise when they are victims of crime). *“People with autism are being manipulated and coerced by criminals to commit crimes they have no understanding of- even if they have high IQ. I have a university degree but was naive when someone asked me to hold a brown paper bag full of drugs. He told me there was 'stuff' in the bag and I believed him. It was only when I told the story to someone else they told me it was illegal and I could have been convicted of assisting with drug dealing.”* (ID 60)	10%
9	**Limited identification or understanding of undiagnosed autism and/or co-occurring conditions** (e.g., behaviours of undiagnosed autistic people may be misinterpreted as criminal; lack of understanding around higher incidence of mental health challenges in autistic population). *“Lack of understanding of co-occurring conditions”* (ID 910) *“[Many] incarcerated people would qualify for a diagnosable mental health "disorder" many are undiagnosed neurodivergent”* (ID 974)	7%

Question 2: What do you think is causing these problems and sample quote from responses

Rank	Factors causing the problems experienced by autistic people in relation to the justice system and sample quotes from responses	% of all respondents who stated this issue
1	**Lack of autism training/education to enhance knowledge, minimise misinterpretations or address stigma/assumptions** (e.g., lack of training for police on autism; lack of understanding/awareness of autism within the justice system). *"Police are improperly trained regarding interactions with autistic people and misidentify autism symptoms as drug use or uncooperative behaviour."* (ID 81) *"Lack of training regarding neurodivergent needs and accommodations."* (ID 1471)	57%
2	**Limited adjustments or accommodations provided or available to autistic people accessing the justice system** (e.g., adjustments not made in prisons and courts; lack of safe spaces away from crowds). *"Disability rights and reasonable adjustment not being applied consistently throughout Australia's justice systems."* (ID 937) *"Sensory overload. For example physical contact from strangers being unpleasant and uncomfortable for people with Aspergers."* (ID 1481)	19%
3	**Funding limits access to supports and services for autistic people accessing the justice system** (e.g., Legal Aid is busy and has too many cases to get through). *"Not having full legal aid help available here in Australia for low-income earners."* (ID 153)	15%
4	**Policy, laws and systemic issues governing the justice system** (e.g., the justice system does not listen to the community). *"Lack of desire to be inclusive. A culture of exclusion and suppression of marginalised groups."* (ID 195) *"Systemic disrespect for anyone in trouble with the law – treated like a 'criminal' even before trial and it is very distressing for a person with autism."* (ID 897)	13%
5	**Justice system is based on neurotypical norms and expectations** (e.g., concepts of criminal or untrustworthy behaviour are centred on neurotypical norms; the structure of the justice system is designed for neurotypical/male people; justice system doesn't cater for those who struggle with self-advocacy/communication). *"Neurotypical bias of systems, processes, policies, expectations."* (ID 699) "*Neurotypical world view which feeds stigma and discrimination against autistic people. For example, in a court room, an autistic person giving evidence may not give eye contact, look around, have pauses between questions, answer questions without hearing them and require questions be repeated. Neurotypical people in a jury could view these behaviours as showing the witness is untrustworthy, not telling the truth etc."* (ID 873)	10%

6	**Undiagnosed autism and no pathway to receive a diagnosis with justice system** (e.g., lack of diagnosis of autism; lack of diagnosis of co-occurring conditions). *“Law enforcement is not equipped to deal with undiagnosed disabilities such as ASD.”* (ID 60) *“[Autism] assessment of people in judicial system is flawed and inadequate.”* (ID 1499)	7%
7	**Autistic people experiencing ableism and other forms of discrimination/indifference from those in justice system** (e.g., discrimination of those with intersectional identities; police aggression). *“Systemic issues and intersectional discrimination.”* (ID 637) *“Police too aggressive and not listening (I have physical bruises and cuts).”* (ID 1475)	7%
8	**Autism characteristics may increase vulnerability to becoming involved in justice system** (e.g., criminals identify autistic people as gullible and exploitable; autistic people can experience grooming and predatory behaviour). *“Vulnerability to social isolation and malicious group influences.”* (ID 492) *“Not being able to differentiate between who is a ‘good’ friend and who is a ‘bad’ friend.”* (ID 1212)	6%

Question 3: What do you think could prevent or reduce these problems?

Rank	Factors that could prevent or reduce the problems experienced by autistic people experienced by autistic people in relation to the justice system and sample quotes from responses	% of all respondents who stated this issue
1	**Provide education/training to improve awareness, understanding and knowledge of autism, associated characteristics and how to work with/support autistic individuals in the justice system** (e.g., knowledge of how to respond to autistic people; training for police). *"We need to provide more education to lawyers, [m]agistrates, barristers and anyone else involved in the justice system around autism and how we could be better supported during what most likely could be the lowest point in our lives as victims or accused."* (ID 400) *"Education and professional support about what it means to live with autism, how to communicate effectively with people with communication difficulties, and the implication of living with sensory issues and other factors that impact behaviour and experience in the world."* (ID 1308)	63%
2	**Improve access to appropriate and sufficient supports across areas (i.e., social supports, legal supports, other professionals supports, mental health, written information)** (e.g., extra time to process questions; not needing to attend court in person; access to support people). *"Disabled people should automatically be granted [...] a case worker/social worker to help them understand what is happening."* (ID 81) *"Provision of information pamphlets with photos of the court environment and information about procedures. Provision of an information pamphlet explaining procedures when police are involved e.g., witness interview, what happens when arrested, explain protective custody."* (ID 1546)	20%
3	**Amendments needed to the policy, laws and systemic issues governing the justice system** (e.g., policy reform to be more inclusive of difference; reform to state discrimination laws) *"Severe punishments for those that use force against autistic meltdowns"* (ID 277) *"Law reform and embedded processes on recognising and understanding ASD in the legal system for both criminal and civil matters."* (ID 616)	15%
4	**Foster the use of an individualised approach and accommodation of individual needs** (e.g., use of interpreters when communication is difficult). *"Well we've busted our a**es in recent years trying to mitigate [state police] responses to my son's incidents by application for an interagency response team of [state ambulance services] and [state police] in a tiered response plan to attend the house instead of [supported independent living] staff calling [state police]alone for emergency assistance when negotiation between my son and his staff fails (2:1)"* (ID 1119)	15%
5	**Develop ways to positively impact broader community/societal factors that increase autism acceptance or awareness** (e.g., more widespread information about autism; public education about autism). *"Education including community awareness program"* (ID 47)	10%
6	**Ensuring the perspectives of autistic people are included in training/education or decisions about the justice system** (e.g., education about autism from neurodivergent/autistic individuals; including the voices of autistic people in police training). *"Voice of autistics in police training and ongoing learning."* (ID 1127) *"Education and training from Autistic lead organisations."* (ID 1512)	8%

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

Question 4: What is working well, or has worked well, in relation to autistic people accessing the justice system?

Rank	What is working well, or has worked well, in relation to autistic people accessing the justice system and sample quote from responses	% of all respondents who stated this issue
1	**Nothing is working well/has worked well** *"Nothing is working because normally if you get too emotional you are put on a Psych hold and therefore are demeaned and ignored over your true innocence."* (ID 793) *"Nothing from what I hear. Jailing a 19 year old autistic boy for 9 months is NOT the solution to him having aggression."* (ID 860)	45%
2	**When there is autism-specific knowledge, awareness, and understanding of professionals in the justice system gained via training and first-hand knowledge and experience** (e.g., when front line workers understand autistic behaviours; when court social workers are aware of barriers autistic people face). *"I've found police officers who have autistic children/family are able to identify early and be supportive rather than authoritarian."* (ID 381) *"Most police in the field we have come across are very understanding and knowledgeable."* (ID 587)	23%
3	**When there is access to support people/advocacy** (e.g., the use of intermediaries for witnesses; access to disability advocates). *"Autistic people can generally have support persons present with police interviews and when giving evidence."* (ID 866) *"Court [liaison] officers who understand autism are gold."* (ID 1167)	20%
4	**When there is access to other supports within the justice system** (e.g., links between the justice system and the NDIS; support animals/therapy animals in court). *"[When] paperwork is helped with."* (ID 858) *"Separate listings in court to the regular listings (for example the ARC [Assessment and Referral Court] List in the Magistrate's Court in Victoria)."* (ID 1365)	16%
5	**"Don't know"** *"I don't know but minorities are at a disadvantage."* (ID 196) *"Don't know, sorry."* (ID 1269)	11%

Appendix I-2: Umbrella review search terms

The following search terms were used for the respective databases:

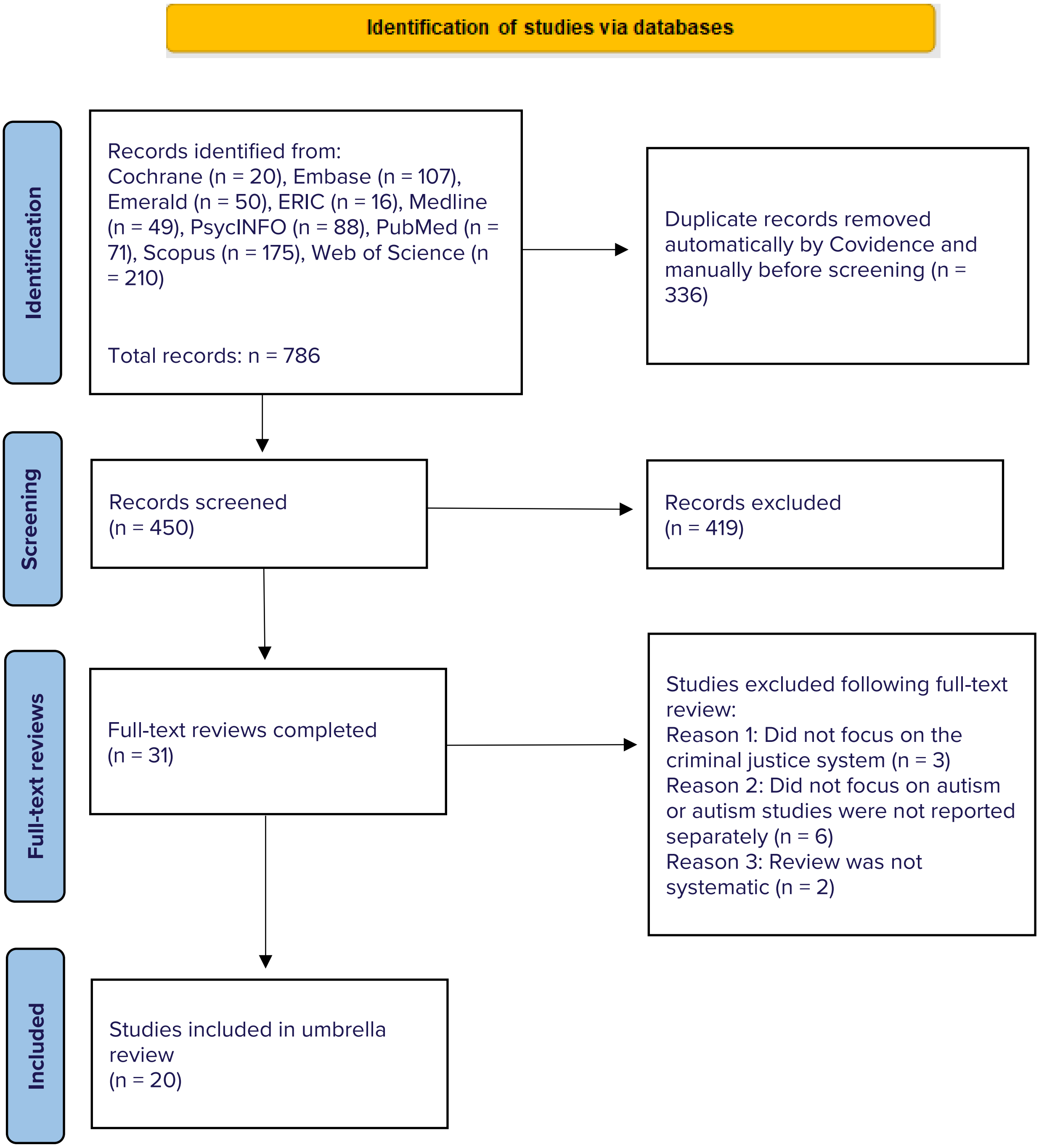
Cochrane, Embase, Emerald, ERIC, Medline, PsycINFO, PubMed, Web of Science

(autis* OR ASD OR ASC OR Asperger* OR pervasive developmental disorder OR PDD) AND (CJS OR Prison OR Probation OR Court OR Secure OR Forensic OR Crim* OR Offen* OR Correction* OR Witness OR justice OR victim OR legal OR law OR police OR judicial OR court* OR sentencing OR judge OR law enforcement OR delinquents OR secure OR HSPC OR Custod*) AND (systematic review* OR scoping review OR narrative review OR systematic literature review* OR systematic quantitative literature review OR evidence synthes* OR meta-analy* OR meta-regression*)

Scopus

(autis* OR ASD OR ASC OR Asperger* OR “pervasive developmental disorder” OR PDD) AND (CJS OR Prison OR Probation OR Court OR Secure OR Forensic OR Crim* OR Offen* OR Correction* OR Witness OR justice OR victim OR legal OR law OR police OR judicial OR court* OR sentencing OR judge OR “law enforcement” OR delinquents OR secure OR HSPC OR Custod*) AND (“systematic review*” OR “scoping review” OR “narrative review” OR “systematic literature review*” OR “systematic quantitative literature review” OR “evidence synthes*” OR meta-analy* OR meta-regression*)

Appendix I-3: PRISMA diagram



Records identified from:
Cochrane (n = 20), Embase (n = 107), Emerald (n = 50), ERIC (n = 16), Medline (n = 49), PsycINFO (n = 88), PubMed (n = 71), Scopus (n = 175), Web of Science (n = 210)

Total records: n = 786

Duplicate records removed automatically by Covidence and manually before screening (n = 336)

Records screened
(n = 450)

Records excluded
(n = 419)

Full-text reviews completed
(n = 31)

Studies excluded following full-text review:
Reason 1: Did not focus on the criminal justice system (n = 3)
Reason 2: Did not focus on autism or autism studies were not reported separately (n = 6)
Reason 3: Review was not systematic (n = 2)

Studies included in umbrella review
(n = 20)

(Template from Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D et al. (2021). The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. *BMJ, 372* (71). doi: 10.1136/bmj.n71)

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Appendix I-5: Policy search strategy

Step 1	• Criminal Justice System sectors were identified using the Parliament of Australia website: https://www.aph.gov.au/About_Parliament/Parliamentary_Departments/Parliamentary_Library/pubs/rp/rp1819/Quick_Guides/Crime • Federal departments, oversight bodies, and professional associations were searched. • All legislation in force was searched using the Federal Register of Legislation: https://www.legislation.gov.au/
Step 2	• Key documents (including policies, guidelines, plans, and statements) relating to the national sectors and sub-sectors identified were sourced from Federal Department websites, related • Key documents were searched for the terms “autis*”, “disab*” and related terms defined within the documents (e.g., “cognitive impairment”, “mental incapacity”). Relevant sections were extracted.
Step 3	• Relevant State and Territory government departments and registers of legislation were searched as well as state-based representative bodies for the legal profession. • Key documents (including policies, guidelines, plans, and statements) were sourced. Key documents were searched for the terms autis* and disab* and related terms defined within the documents (e.g., “cognitive impairment”, “mental incapacity”). Relevant sections were extracted. • Documents mentioning disability only in relation to workplace hiring policies within the sector were excluded, as were plans or strategies that were no longer current.
Step 4	• A general Google search was then conducted to ensure that key documents had not been missed during Steps 1-3.

Appendix J: Mental health services

Appendix J-1: Content analysis categories

Question 1: What are three problems that autistic people experience when accessing, or trying to access, mental health care services?

Rank	Problems experienced by autistic people in relation to using or trying to access mental health services and sample quotes from responses	% of all respondents who stated this issue
1	**Insufficient availability/access of relevant, skilled mental health worker** (e.g., lack of providers who can do assessments; challenges finding neurodivergent therapist) *"Not enough access to Occupational Therapists who can help open the door to more needed mental health help."* (ID 153) *"Access to enough psychologists for assessments and therapies because only a small number of psychologists are endorsed 'clinical'"* (ID 555)	24%
2	**Lack of knowledge or understanding of autism/neurodiversity, its presentation, and its impact across the lifespan** (e.g., lack of knowledge about autism in females; lack of understanding of lived experience) *"Very few psychologists understand autism. Even fewer understand pathological demand avoidance. Psychologists who don't understand autism can cause harm."* (ID 955) *"Most mental health service practitioners do not have enough knowledge about autism (especially as it presents in women) to be able to tailor mental health support appropriately."* (ID 1159)	23%
3	**Prohibitive cost** (e.g., very expensive; services able to charge too much) *"I am horrified by the concept of "bulk billing" and "gap fees" - Australia is meant to be a First World country. Waiting lists are to be expected, but many people who need mental health support the most have given up hope of ever accessing support because they can't afford the gap fee."* (ID 68) *"Costs can be prohibitive for some families given the long-term nature of mentoring required for some clients."* (ID 380)	22%
4	**Long or closed waitlists** (e.g., long waiting time to access diagnostic services, psychologists and psychiatrists; waiting lists exacerbate issues) *"General wait time to start seeing a psychiatrist in our area is 18 months. It took 8 months for us to get an appointment with [a] psychologist."* (ID 30) *"Mine is the wait time. I needed to see/talk to my psychotherapist with an issue in early March. My appointment is in mid May."* (ID 1329)	21%

5	**Insufficient availability/access of appropriate services** (e.g., lack of services specialising in autism; long distance to travel) *“Services [are] often geographically difficult to access requiring children to miss a lot of school to attend appointments and parents to miss work to drive children to and from appointments (in my case having to move to part-time work to support driving my child to appointments)”* (ID 1131)	20%
6	**Misdiagnosis of autism and/or co-occurring conditions** (e.g., misdiagnosing autism as, for example, a personality disorder; diagnostic overshadowing) *“I've been in and out of therapy my whole life, at one point was diagnosed with emotional [deprivation] disorder. I had an inkling when my daughter was small and I saw it in her then [realised] it was me too. I think I suggested it in therapy but it must have seemed absurd to the psychologist. Now I know, and I know my (dec) partner was autistic and that my mum likely is and so on.”* (ID 477) *“I've seen professionals for years and been misdiagnosed with anxiety, social anxiety, depression, and PTSD. I have none of these conditions.”* (ID 1346)	10%
7	**Lack of knowledge or understanding of the interaction between autism and co-occurring conditions including mental health problems** (e.g., lack of knowledge of mental health issues and experiences for autistic people; lack of understanding of co-occurring conditions including ADHD and mental health) *“Finding a competent mental health professional that really understands the autistic experience of comorbid conditions such as anxiety, OCD, depression - that the autistic expression of these conditions may be different, especially if they also have intellectual disability.”* (ID 91)	7%
8	**Strategies not tailored for the individual client or neurodivergent people** (e.g., not tailored for individual needs or preferred goals; neurotypical strategies do not always work for autistic people) *“Mental health workers often try to use regular interventions like CBT which isn't always suitable for neurodivergent people, or they're not well versed in what autistic people actually need. One example is being asked "Where do you feel that in your body?" Well, autistic people sometimes don't feel like things hunger etc, how can we be expected to know where we feel a feeling, that usually we struggle to even name the feeling in the first place”* (ID 288)	7%
9=	**Access refused due to autism diagnosis** (e.g., refusal of autistic client for fear of doing harm; services do not support autistic people) *“CAMHS (Child and Adolescent Mental Health Service - WA) refusing to support children and teenagers with ASD who also have mental health concerns. Referrals are often knocked back purely on the basis of disability without taking into account the individuals mental health needs.”* (ID 410) *“Professionals may feel fearful of doing harm and therefore refuse to see individuals with autism, restricting [the] number of providers able to assist.”* (ID 643)	6%
9=	**Challenges accessing services due to lack of support, knowledge, or accommodations** (e.g., challenges navigating the services; challenges booking appointments by telephone)	6%

	"Executive dysfunction that some autistic people experience can mean that finding a psychologist with availability and expertise can take a very long time or assistance is required from a support person. It can mean sending emails about appointments or reports can take weeks or months to send, which for a neurotypical person could take 5 minutes." (ID 873) *"It's always phone calls to try and access services so I often just don't."* (ID 1081)	
9=	**Professionals may make assumptions or have preconceived ideas of autism, holding a deficit based view** (e.g., stereotyping; behaviours viewed as attention seeking) *"The surprise when health professionals finally see me when my disability becomes impactful because of increased stress as [they] assume that I wasn't as disabled as I told them."* (ID 940)	6%
12	**Mental health services not providing autism diagnosis or recognising autism characteristics** (e.g., challenges obtaining referral for diagnosis; lack of identification of autism characteristics) *"Finding someone to interview me and diagnose me was a long process. I know many people who are still struggling for that recognition and a way to pay for it."* (ID 72) *"Read the autobiographies [of] autistic women... they are disturbingly similar... trying and trying to get help but being repeatedly misdiagnosed...I've seen psychologists and psychiatrists in the last 10 years, including the last 5, NONE of whom ever raised the prospect of autism. I discovered it myself, frankly, through reading Hannah Gadsby's autobiography. So many mental health professionals don't see autism in women when it is staring them in the face."* (ID 1170)	6%
13	**Challenges co-ordinating/accessing funds to support mental health access (beyond NDIS)** (e.g., no Medicare support; limited bulk billed sessions; difficulty co-ordinating funding options) *"Counselling is not funded through Medicare, this needs to be fixed to address access to mental health services"* (ID 709) *"Not all Autistic people are working and therefore cost can be a barrier to obtaining the supports they need. NDIS is pushing Autistic participants to use a mental health plan which is only subsidised visits and not everyone can afford the out of pocket expenses."* (ID 753)	6%
14	**Challenges accessing and using funds through NDIS** (e.g., support only for ASD level 2 or higher; difficult to access psychology under NDIS) *"NDIS refuse to accept that mental health problems can be related to autism (anxiety, trauma etc.) and will not fund support for same"* (ID 188) *"The way NDIS funding is misappropriated by physicians and service providers. Charging the (higher) NDIS rate instead of their standard rate marginalises the client and their funding does not go as far, thus preventing them from treatments. Psychologists are extremely guilty of this."* (ID 515)	6%
15	**Concerns about professional's therapeutic skills** (e.g., lack of genuine care; discriminatory towards autistic people) *"Finding a provider that I trust and will communicate clearly and compassionately without assumptions or patronising me."* (ID 1100) *"Nothing I said was believed. All of my very real distress and suicidal thoughts were minimised and dismissed because it was thought I was lying or exaggerating for attention."* (ID 1440)	6%

16	**Trivialising or not believing someone's autism diagnosis or their lived experiences** (e.g., not believing someone's experience) *“Professionals making light of diagnoses during appointments "Oh, there's the ADHD/ASD - I've lost you." This has actually happened to my child.”* (ID 447) *“There seems to be an urge to test the diagnosis you were given to see if it is right. If you need mental health care, what does it matter? That should come first.”* (ID 495)	6%
17	**Strategies and practices considered insufficient, inappropriate or poor quality** (e.g., reliance of medication; symptoms treated not the root cause) *“It is very medically focused. The emphasis is always on the drugs that should be prescribed.”* (ID 1016) *“Mental health providers telling parents to take a behavioural approach to supporting their autistic children. This is so wrong and out of touch, and cruel.”* (ID 1335)	6%
18	**Lack of autism training** (e.g., lack of regular autism training; lack of training provided by autistic people) *“Autism is not taught in the relevant schools, it is up to individual medical practitioners to proactively explore the subject.”* (ID 311) *“Ableist, outdated understanding of autism - inadequate training in treating mental health conditions in autistic people”* (ID 1525)	5%
19	**Lack of neuro-affirming practice** (e.g., encouraged to function in neurotypical way; trained to mask) *“Non neuro-affirming practices that encourage people to be "less autistic".”* (ID 194) *“Often autistic people are seen as "broken" or in need of "fixing". Many therapies suggest that autistic people "mask" their autistic traits which is terrible for the person's wellbeing and long-term outcomes.”* (ID 681)	5%
20	**Lack of communication between sectors/professionals leading to falling between the cracks and/or frustration** (e.g., bounced between services; poor interaction between child and adult services) *“There is an appalling level of needing to "repeat your story" entering any mental health service and frequently unnecessary duplication of assessments.”* (ID 354) *“Not being treated as a 'whole person', ie. falling in the gap between mental health services and disability services because you require both but they are not coordinated and/or pass the buck between each other”* (ID 1464)	5%

Question 2: What do you think is causing these problems?

Rank	Factors causing the problems experienced by autistic people in relation to using, or trying to access, mental health services and sample quotes from responses	% of all respondents who stated this issue
1	**Lack of, or poor quality of, training for mental health professionals** (e.g., poor training; lack of training in diagnosing and treating autism appropriately) *"Lack of education leads to a lack of accommodations leading to a lack of appropriate care for neurodiverse people."* (ID 162) *"Psychologists and mental health professionals have not been taught about autistic mental health from autistic made sources"* (ID 816)	23%
2	**Lack of knowledge or understanding of autism and neurodiverse conditions, its presentation, and its impact** (e.g., lack of understanding the heterogeneous presentation of autism; lack of understanding of stresses associated with autism) *"Lack of understanding that autism can be "missed" in childhood, but masking "hides" issues-especially for biological women."* (ID 842)	22%
3	**Insufficient number of professionals with an interest/expertise in autism** (e.g., lack of qualified people specialising in autism; lack of specialists in rural areas) *"There aren't enough general psychologists let alone any that specialise in autism."* (ID 41)	19%
4	**Insufficient funding (generally)** (e.g., lack of funding; funding shortfall) *"Too expensive. Some don't have NDIS but can't afford support, as rates are charged at NDIS prices with no acceptance of GP mental health plans or chronic disease management plans"* (ID 17)	19%
5	**Concern about therapeutic skills and/or attitude** (e.g., lack of respect; ableism; not allowing time to develop relationship; ignorance) *"Busy staff...just ticking boxes etc, without any empathy or humility or desire to truly help improve peoples' lives."* (ID 147) *"Focus on quickly getting assessments and diagnosis rather than relationship and rapport building to understand what the individual's baseline is, and lack of critical engagement with family/caregivers."* (ID 998)	13%
6	**Overwhelmed system/professionals with insufficient resources** (e.g., lack of resources; overwhelmed staff; time pressure) *"EXTREMELY limited resources dedicated to supporting autistic people in a meaningful manner."* (ID 784) *"System overburden and burnout. Clinicians have high caseloads and are time poor. Complexity associated with autism and greater time commitment results in greater unwillingness to work with Autistic people."* (ID 1357)	10%
7	**Strategies and practices considered insufficient, inappropriate or poor quality** (e.g., lack of awareness of how to modify practices; neuronormative concepts of well-being applied to autistic people)	10%

	“Mental health professionals profess to only "treat the mental health condition" with no consideration of how neurodivergence is interwoven and part of the whole person.” (ID 354) *“The promotion of "evidence based" treatments such as CBT and ABA - these do not work for most ND clients.”* (ID 852)	
8	**Impact of decisions made by the government** (e.g., government policies; government cuts; poor management of mental health services) *“Poor government policy and intervention - need clear guidance, programs to ensure service availability, subsidies costs, and better designed medical and mental healthcare systems to ensure early diagnosis by frontline medical, educational or caregiver staff (diagnosis should not rely on self-diagnosed first!).”* (ID 1494) *“Gov't agencies playing a "not my responsibility card" and yoyo'ing people between NDIS, Medicare, Private Health and Public Health.”* (ID 1555)	9%
9	**Lack of knowledge, understanding, or experience of co-occurring conditions including mental health, and their interaction with autism** (e.g., lack of knowledge about, or experience with, mental health conditions, autistic burnout) *“The actions of mental health services and staff just cause more trauma to people with autism. They are incapable of handling me as one human being who has autism, two serious mental illnesses and several chronic physical illnesses.”* (ID 1436)	8%
10	**Insufficient number of, or access to, services** (e.g., lack of services/facilities; gatekeeping; distance for rural people) *“Gatekeeping in psychology training and registration artificially decreasing the number of psychologists…”* (ID 724)	8%
11	**Challenges with Medicare support** (e.g., no funding for autism assessment/therapy for people older than 15 years; out of pocket cost too high) *“Medicare being cut back to 10 again is a good example of a lack of understanding. Our conditions don't just stop. Difficulties navigating a neurotypical world are ongoing, constant, and aren't just going to be fixed with 10 sessions.”* (ID 361) *“Medicare does not cover anywhere near the full cost with gap fees of upwards of $90/session”* (ID 400)	7%
12	**The system is challenging and is not designed to support the access/use of autistic people** (e.g., inflexible; access needs are not enquired about) *“Very often a service is a number for you to leave a message for a call back. A call back usually takes two days or [no] call back. That is a big hurdle for a person with autism to access mental health service.”* (ID 668) *“Lack of information and guidance about accessing mental health services - inconsistency of processes and systems for access (e.g. how to contact, how to set up appointments, how to find information)”* (ID 699)	7%
13	**Challenges with NDIS access, funding, and misuse of funds by professionals** (e.g., NDIS will not support mental health; NDIS planner not understanding the interaction between autism and mental health) *“NDIS will not fund psychology as they believe mental health care plans are sufficient”* (ID 81) *“Privatisation of services under the NDIS model has resulted in a dearth of services [to] support complex cases. It is financially unrewarding for professionals to take on complex cases. Lack of qualified case coordinators and funding models for this, this is a very skilled and crucial role, support coordinators and "specialist support coordinators" very seldom have the necessary skills.”* (ID 643)	6%

14	**Lack of research and autistic-informed care in mental health services** (e.g., evidence base is needed for women and girls; lack of co-designing services with autistic people) *"Lack of autistic input into co designing services"* (ID 248) *"Nowhere near enough research into effective mental health treatment for autistics"* (ID 1525)	6%
15	**Approaches currently focus on medical model rather than more inclusive approaches** (e.g., medical model is a problem; interaction with society is the problem, not autism) *"A failure to consider that our body-mind experiences differ fundamentally and that this is not the problem - the interaction of the outside world and [its] people are. That therapy is enough - it's not (but that doesn't mean we don't need it). Therapy won't cure ableism any more than it will cure racism or any other social issue so long as that issue is still present and impactful on our lives."* (ID 314) *"Australia is a very compliant society and it hasn't got a lot of space for 'eccentricity' so anyone who behaves/presents a little different[ly] can be made to feel like they have a problem rather than being accepted. Mental health services can see their job as helping people with autism learn to fit in more (this seems to be an unconscious but consistent thread)"* (ID 897)	6%
16	**Challenges around diagnosis** (e.g., late diagnosis; lack of acceptance of self-diagnosis; misdiagnosis of autism) *"There is currently a catch-up happening with older women who weren't diagnosed as children despite their obvious autism. The waiting lists for the appropriate, trusted professionals who can diagnose [older] women are huge. The catchup period post-covid and lockdowns isn't helping either"* (ID 330) *"Professionals in support fields seem to believe that a diagnosis makes a person autistic, rather than accepting self-identification as valid."* (ID 446)	6%
17	**Increase quality in training, and number of students, focusing on mental health at university and/or further education** (e.g., more clinical psychology places needed; more effective training for mental health professionals) *"Psychologists are not taught at university much about autism and are certainly not taught about affirming therapy and what therapy modalities work best for autistic people which is different for neurotypical people."* (ID 90) *"Qualification parameters for psychology [are] too restrictive to quickly increase the amount of psychologists in Australia."* (ID 987)	6%
18	**Professionals may make assumptions or have preconceived ideas of autism** (e.g., autistic people are not competent; autism is a "male diagnosis") *"Some professionals don't think adults are autistic."* (ID 1081)	5%
19	**Some autism characteristics (or associated characteristics) may make it challenging to attend/engage in therapy** (e.g., avoid social interactions; difficulty communicating mental health concerns) *"Autistics may find it difficult to be open in discussing their mental health, particularly if they are used to masking their true selves."* (ID 187) *"I'm a nervous driver, especially when travelling somewhere I don't know, combined with already being very afraid of all things medical it makes in person visits near impossible"* (ID 977)	5%

Question 3: What do you think could prevent or reduce these problems?

Rank	Factors that could prevent or reduce the problems experienced by autistic people in relation to using or trying to access mental health services and sample quotes from responses	% of all respondents who stated this issue
1	**Increase (access to) training for people working as mental health professionals to enhance their understanding of autism (and other neurodivergence), including training from autistic people with lived experience** (e.g., mandatory, regular training; autistic informed/delivered training) *"Better education of training psychologists both to better understand autism and its different presentations and best evidence therapies for autistic clients and of neuro affirming practices. Ideally this should come from the voices of the handful of autistic psychologists currently practicing that are leading this movement."* (ID 90)	42%
2	**More mental health professionals, including those specialising in autism, and those who are autistic/neurodivergent themselves** (e.g., more doctors; more psychologists; create new roles and professions to support autistic people; incentives for experts; alternative qualification pathways) *"Government to address the lack of psychological services in the community i.e. allow provisional psychologists to be covered by Access to Mental Health Care plan sessions to increase numbers in the community and continue to improve services" (ID 1204)*	20%
3	**Increase funding and/or affordability of mental health services across the lifespan** (e.g., government funded functional capacity assessment; price caps and/or rebates) *"The Government needs to properly fund mental health services, so that when autistic people need their services, they are not simply referred back to their NDIS providers." (ID 532)* *"Somehow reducing the cost of things like therapy and having more psychologists/positions for psychologists available." (ID 882)*	19%
4	**Improve access to, and quality of, services** (e.g., reduce the red tape; consideration of access for regional and rural areas; services for people with complex needs) *"Have more mental health services available for transition from early childhood, to primary and secondary school, then a big increase at [the] end of high school. Transition to adult services when done effectively early, will ultimately benefit the young person with Autism and also place less strain on the medical system down the track." (ID 559)* *"There should be the ability to access psychosocial support whenever needed once a diagnosis is given. Kind of like an unlimited referral that sometimes can be given for other specialists" (ID 963)*	12%
5	**Enhance the quality of university education and number of places availability** (e.g., do not phase out psychology general registration pathway; provide education on neurodiversity-affirming practice; include information on co-occurring intellectual disability and other co-occurring conditions) *"Increase the number of university places for mental health professionals- especially psychologists AND ensure the general registration pathway (honours degree + 2-year internship) pathway is not phased out." (ID 60)* *"Psychology and psychiatry curricula need mandatory information about autism." (ID 1092)*	11%
6	**Enhance the therapeutic skills and awareness of mental health professionals to support their work with autistic clients** (e.g., listen (and believe) to the client to identify challenges; account for possible challenges in identifying emotions or forming trust)	10%

	"Listening to the individual or working their psych magic to discover what's not ok and changing course when required. Giving time and space. Being creative. I've learnt a lot with toys and characters and truly benefit from a psychologist who helped me by using early childhood things like a 'circle of friends'" (ID 185)	
7	**Facilitate changes to practice to focus on strengths, neurodiversity affirming care, and skills relevant to supporting autistic people** (e.g., use social model rather than medical model; neurodiversity affirming practice) *"Stop looking at behaviour and search for unmet needs" (ID 17)* *"Use of universal strategies that would enable any struggling individual to thrive - soothing environment, reduced demands, genuine relational basis, thorough skill building, individually tailored program NOT providing short term superficial and inconsistent program or supports that reinforce fear of change and experience of failure." (ID 581)*	10%
8	**Make access and use of services easier and more autism-friendly** (e.g., alternative methods to book appointments, increased flexibility of appointments; environment) *"Autistic people need more options around the structure and timing of mental health appointments, such as shorter, more frequent appointments, or appointments that are not conducted in real time (like audio message appointments)." (ID 290)* *"Ensure that clinics and such are warm, welcoming spaces that are sensitive to the sensory needs of people with autism" (ID 1004)*	9%
9	**Implement NDIS specific improvements for funding access** (e.g., more inclusive funding; automatic access to NDIS for autistic people) *"NDIS needs to accept more high functioning autistic people and ALWAYS APPROVE weekly psychology for autistic people" (ID 81)* *"My son is diagnosed with ASD, PDA, OCD, PTSD, and Cluster B personality disorder. He keeps falling through bureaucratic cracks because he receives the NDIS for Autism/OCD which doesn't cater to his mental health diagnoses" (ID 1119)*	7%
10	**Implement Medicare-specific improvements for increasing affordability of mental health care** (e.g., allow provisional psychologists to work under Medicare; Medicare funding for mental health) *"Medicare and state health service models need to move towards activity and funding models that accommodate and reward complex, integrated care" (ID 373)* *"Bring back the extra sessions available with a Medicare rebate on a mental health care plan." (ID 1324)*	7%
11	**Government reform and support of mental health sector** (e.g., legislation around language use; better legislation for protecting clients against poor treatment) *"Standards of care- legislation even around language used"* (ID 56) *"A business case supported by data and financials that demonstrate the value in supporting these efforts and the impact it will have on individuals, societally and economically."* (ID 144)	6%
12	**Improve communication and integration between professionals and/or sectors** (e.g., coordinated approach across NDIS, health, and education; integrated/coordinated health and disability services) *"Coordinated responses between health services - rather than everyone pushing back on other departments, resulting in individuals falling through the cracks."* (ID 163)	6%

	“Restructure health services to provide [a] trans disciplinary holistic approach. Particularly in the teen years where behaviours and social issues need to be considered not as a troubled teen but able to screen/recognise/ understand there's something else going on here.” (ID 1301)	
13	**More co-produced research that provides evidence-based practices for neurodivergent people** (e.g., include autistic and neurodivergent people in research design; research needed into neuro-affirmative practice) *“Extensive research into 'what works' for autistic mental health care & suicide prevention”* (ID 166) *“Grass roots research. Get the community voice to gain an accurate understanding of what people are experiencing and what they need to live functional lives”* (ID 592)	6%
14	**Education to support general public's understanding of autism** (e.g., address stigma; publicity drives to debunk myths and attitudes) *“The normalisation of difference in the workplace and social spaces.”* (ID 940) *“...removing stigma and increasing understanding in the community would diminish the perception of some behaviours as maladaptive and would instead promote acceptance reducing the likelihood of emotional escalation that might then be considered as requiring professional input. Put accessible information in the environment!”* (ID 1014)	6%

Question 4: What is working well, or has worked well, in relation to autistic people accessing mental health services?

Rank	What is working well, or has worked well, in relation to autistic people accessing mental health services and sample quote from responses	% of all respondents who stated this issue
1	**Nothing/Not a lot** *"In our experience of accessing mental health services for our son, I can honestly say that there has been nothing that has worked well. We have been constantly left trying to navigate/fight a broken system, whilst trying to keep our son alive." (ID 48)* *"Nothing is working well, the cost is unaffordable and the waiting times are causing higher rates in suicide and trips to the ER where they are not receiving sufficient help with mental health, only a band aid solution and sent home with tablets." (ID 528)*	21%
2	**When you find the right mental health professional for you, who is often knowledgeable/experienced about autism and its associated needs** (e.g., understands autism and neurodiversity; experience working with autistic people) *"Extremely well trained and experienced mental health practitioners and psychologists are a godsend. Just brilliant." (ID 935)* *"When you find an attuned social worker/psychologist who really 'gets' what it is like to be autistic and the level of anxiety that can permeate every aspect of daily life, you can really start to make therapeutic headway into teaching / learning strategies that will support during a crisis." (ID 963)*	19%
3	**When NDIS once funding has been provided to support needs** (e.g., NDIS can reduce mental health burden when all needs are covered; supportive NDIS plan manager) *"NDIS supports can generally and holistically reduce mental health burden when all needs are covered and assisted with. Prevention is better than cure. In this way NDIS is fantastic and will probably save the government money due to less crisis intervention later down the track" (ID 60)* *"NDIS has provided a new method for autistic individuals who are supported by the NDIS to access psychology services without personal financial cost." (ID 1203)*	15%
4	**When alternative/Flexible Access are available (inc. making appointment and practice)** (e.g., online chat services; alternative booking options such as leaving voice message or online portal) *"More mental health practitioners are offering flexible appointment structures using tools like online portals where patients can upload images/writing, and audio message programs like Voxer." (ID 290)* *"Access to Telehealth services is an important step forward, particularly for autists, and family members who may experience anxiety related conditions and /or depression" (ID 937)*	10%

5	**Support from the family, friends, and autistic/neurodivergent community** (e.g., parent advocacy; ability to bring trusted person to appointments; social groups to meet other autistic people) *“The best thing I experienced was going to an Aspergers support group for adults on the spectrum.” (ID 406)* *“Parents who can afford private services. Parents who jump up and down and push for access. Parents who advocate” (ID 773)*	8%
6	**When a professional has lived experience** (e.g., are autistic/neurodivergent, or have autistic family members). *“I am happy to say that I can now access a psychologist through my NDIS plan and the best thing is they are on the spectrum themselves so I am really comfortable talking to them, however this has not always been the case.” (ID 400)* *“I happened to have an autistic psychologist once and he was the most helpful psychologist I have ever had. I had never really made any progress with counseling before and usually it made me feel worse so I would stop going. Just from my experience I would say that an autistic psychologist is better for an autistic person, than a neurotypical psychologist.” (ID 1328)*	7%
7=	**The recent shift towards neurodiversity affirming and strengths-based practice, rather than relying on medical model.** (e.g., focus on the strengths of a person rather than the challenges) *“Focusing on the person's wellbeing and how to support improved wellbeing rather than functioning like [a neurotypical]” (ID 164)* *“Psychologists who write things like "Mary thrives in fast-paced environments" to describe an extremely ADHD autistic person! Such professionals can really help identify areas that the autist will thrive in long-term.” (ID 1269)*	7%
7=	**A range of different approaches and modifications highlighting that no single approach is suitable for everyone** (e.g., trauma-informed; assistance animals; art therapy; social skills sessions; psychotherapy; group sessions) *“Professionals who are flexible and use alternative methods such as Equine therapy, using an assistance dog, OTs that have gym equipment for regulation during session[s]. The traditional "talking" therapy doesn't work.” (ID 359)* *“Art, music, activities in sessions - making art in therapy is helpful because it externalises the focus of therapy onto the art object. [...]. Engaging senses in soothing activities also helps contain and nourish people so that they don't feel as exposed and they can feel calmer.” (ID 897)*	7%
7=	**When you develop a safe, trusting, therapeutic relationship** (e.g., feeling safe; building long-term relationship; continuity of care) *“Seeing the same person locally for some years has been really helpful to make progress, it takes months to warm up to a new person.” (ID 942)* *“Once you find "your person", the neurodivergent person feels safe and things can change.” (ID 974)*	7%

10	**When a professional has good therapeutic skills** (e.g., compassionate, flexible, listens, patient, speaking calmly) *"Speaking calmly and patience" (ID 858)* *"An empathetic person…Someone who can prompt or assist them to complete all the necessary steps instead of giving up due to depression." (ID 1481)*	5%
11	**A range of different services, including crisis helplines, autism specific services, and community services** (e.g., Kids Helpline; community services) *"…when I accessed a free counselling service through Carer's WA, the Counsellor specialised in parents (many Autistic) with newly diagnosed Autistic kids - helping those parents, without judgement or trying to change them. I felt heard and supported."* (ID 1251) *"Support lines in particular Lifeline when someone is in an active crisis (some better then others)"* (ID 1351)	5%
12	**Increased awareness of autism/neurodiversity and benefits of mental health support** (e.g., awareness of female presentation; prevalence of mental health conditions for autistic people) *"Realising the connect between anxiety, sensory and social autistic challenges."* (ID 163) *"Reduced stigma in community to access mental health services"* (ID 705)	5%

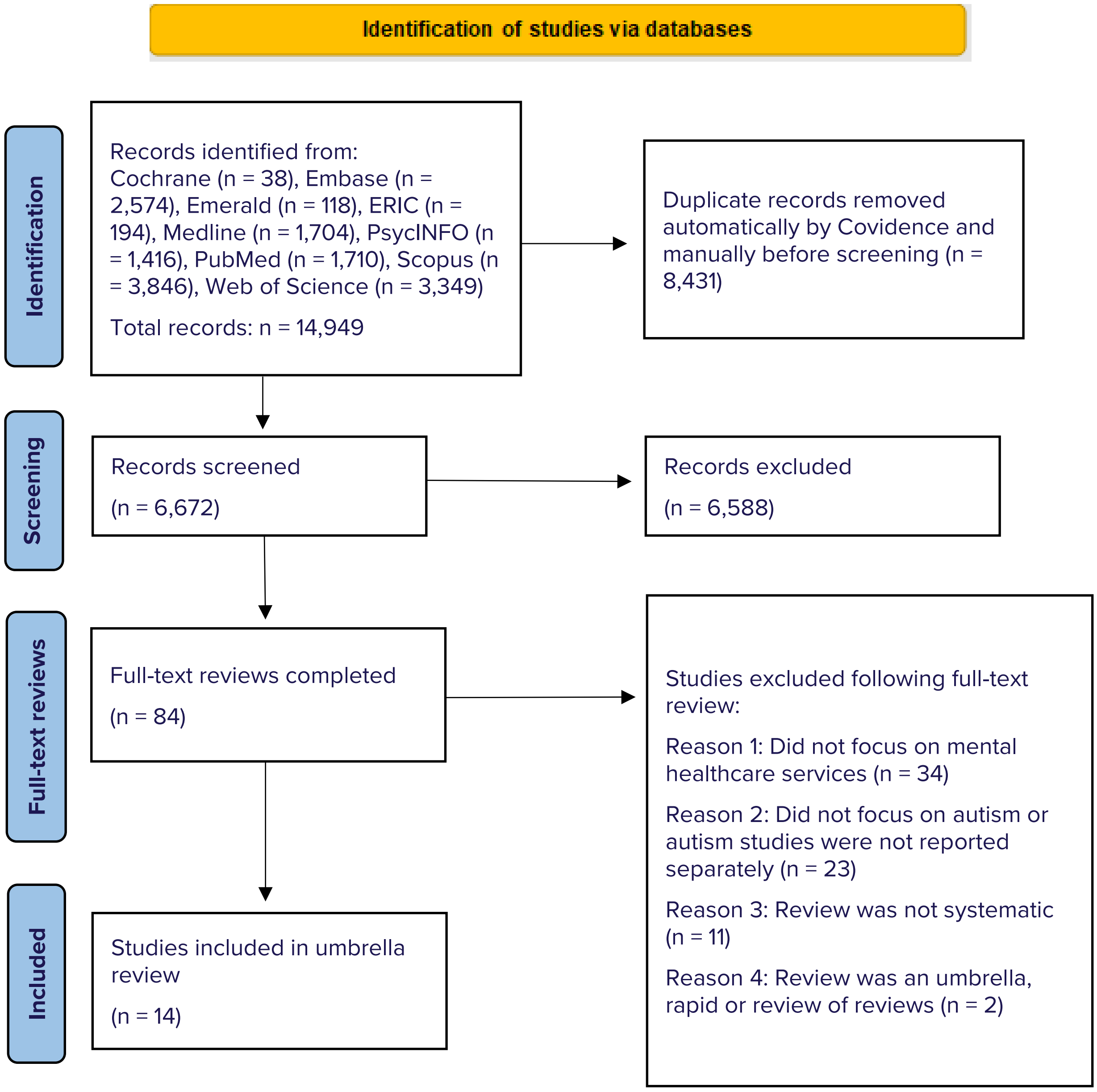
Appendix J-2: Umbrella review search terms

The following search terms were used for the respective databases:

Cochrane, Embase, Emerald, ERIC, Medline, PsycINFO, PubMed, Web of Science
(autis* OR ASD OR ASC OR Asperger* OR pervasive developmental disorder OR PDD) AND (mental health* OR mental ill OR psych* OR comorbid* OR cooccur* OR comorbid OR co-occur* OR therap* OR practitioner* OR clinician OR telehealth OR telemental* OR telepsych* OR allied health* OR anxi* OR depress* OR trauma* OR eating disorder* OR PTSD OR mood disorder* OR bipolar OR mani* OR tic OR tics OR treatment OR inpatient OR in-patient OR outpatient) AND (systematic review* OR scoping review OR narrative review OR systematic literature review* OR systematic quantitative literature review OR evidence synthes* OR meta-analy* OR meta-regression*)

Scopus
(autis* OR ASD OR ASC OR Asperger* OR “pervasive developmental disorder” OR PDD) AND (“mental health*” OR “mental ill” OR psych* OR comorbid* OR cooccur* OR comorbid OR co-occur* OR therap* OR practitioner* OR clinician OR telehealth OR telemental* OR telepsych* OR “allied health*” OR anxi* OR depress* OR trauma* OR “eating disorder*” OR PTSD OR “mood disorder*” OR bipolar OR mani* OR tic OR tics OR treatment OR inpatient OR in-patient OR outpatient) AND (“systematic review*” OR “scoping review” OR “narrative review” OR “systematic literature review*” OR “systematic quantitative literature review” OR “evidence synthes*” OR meta-analy* OR meta-regression*)

Appendix J-3: PRISMA diagram



Records identified from: Cochrane (n = 38), Embase (n = 2,574), Emerald (n = 118), ERIC (n = 194), Medline (n = 1,704), PsycINFO (n = 1,416), PubMed (n = 1,710), Scopus (n = 3,846), Web of Science (n = 3,349)

Total records: n = 14,949

Duplicate records removed automatically by Covidence and manually before screening (n = 8,431)

Records screened

(n = 6,672)

Records excluded

(n = 6,588)

Full-text reviews completed

(n = 84)

Studies excluded following full-text review:

Reason 1: Did not focus on mental healthcare services (n = 34)

Reason 2: Did not focus on autism or autism studies were not reported separately (n = 23)

Reason 3: Review was not systematic (n = 11)

Reason 4: Review was an umbrella, rapid or review of reviews (n = 2)

Studies included in umbrella review

(n = 14)

(Template from Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D et al. (2021). The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. *BMJ, 372* (71). doi: 10.1136/bmj.n71)

Appendix J-4: References

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Appendix J-5: Policy search strategy

Step 1	• Mental Healthcare sectors were identified using the Australian Institute of Health and Welfare website: https://www.aihw.gov.au/mental-health/overview/australias-mental-health-services • Sectors were cross-checked and sub-sectors added, where relevant, using the Australian Healthcare Practitioner Regulation Agency (Ahpra) websites: https://www.ahpra.gov.au/Registration/Registers-of-Practitioners/Professions-and-Divisions.aspx
Step 2	• Key documents (including policies, guidelines, and statements) relating to the national sectors and sub-sectors identified were sourced from the above websites and other Federal Department websites (where appropriate). • Key documents were searched for the terms autis* and disab* and relevant sections were extracted. Documents that did not mention autism and/or disability were also highlighted.
Step 3	• The physical healthcare sectors were then searched for on each State and Territory health (as well as other relevant government department or professional body) websites. • Key documents (including policies, guidelines, and statements) were sourced. Key documents were searched for the terms autis* and disab* and relevant sections were extracted. Documents that did not mention autism and/or disability were highlighted as well as if national policies, strategies or bodies governed the respective State or Territory healthcare sectors or approaches.
Step 4	• A general Google search was then conducted to ensure that key documents had not been missed during Steps 1-3.

Appendix J-6: Wellbeing and quality of life systematic review

Systematic review

This protocol was registered with the international prospective register of systemic reviews: "*Whose voice is heard, and whose is missing, in research exploring quality of life and wellbeing of autistic individuals: A systematic review*" PROSPERO 2022 CRD42022385357. The terms used for the searches and the number of articles identified, screened, and included are provided at the end of Appendix G-4.

The systematic review of four academic databases identified 245 articles reporting on the quality of life and/or wellbeing of autistic people. The majority of the studies (34.7%) were conducted in the United States of America. Twenty-four (9.8%) of the 245 research studies were conducted in Australia, and were published between 2012 and 2022, with 21 (87.5%) of the studies published between 2018 and 2022.

Participants within the studies included in this review

In total, the research articles included 49,795 autistic participants, with sample size for studies ranging from 1 to 4,910 (M = 206.62; SD = 469.14). Autistic participants, or the case studies reported, ranged in age from 3 to 83 years. In 84% of the studies, gender was reported for the autistic individuals. Most studies reported gender with binary options; using this, there were proportionally more males than females (average percentage = 71% males). Twenty-two studies (9%) reported on gender diverse individuals.

Quality of included articles

The Quality Assessment with Diverse Studies (QuADS) is being used to appraise the methodology and quality of the studies. The QuADS includes 13 criteria scored on a scale (0 = *no mention* to 3 = *explicit/detailed*), with a maximum score of 39. To date, the articles appraised ranged in quality with QuADS scores between 13 to 35, with an average score of 27, suggesting overall reasonable quality.

Topics of included studies

The focus of this review was to identify, in research that reports on autistic quality of life and or/wellbeing, who is reporting the information, how it is measured, and who is being discussed.

In the studies identified, the quality of life and/or wellbeing of autistic people was reported by autistic people (104 studies), autistic people and others (i.e., parent/caregivers, professionals, support workers; 56 studies), and others (84 studies). Over 80% of the studies relied on questionnaires/surveys to measure autistic people's quality of life and/or wellbeing. The key findings for each topic are discussed in Table 1.

Research gaps

This review identified a number of research gaps, which are described for each topic in Table 1. In brief, autistic people were rarely asked what they viewed as quality of life and/or wellbeing. Very few studies included the voice of autistic people who have an intellectual impairment, or autistic people who identify as nonspeaking or who use alternative communication. The quality of life and/or wellbeing of autistic people was assessed using measures developed for non-autistic populations and findings were reported on normative data. The impact of co-occurring conditions on a person's quality of life was rarely considered.

In addition, other research gaps were noted by the authors of this report. These include that it is not known what autistic people identify as having a good quality of life and/or wellbeing and what influences them in achieving this. The autistic community was rarely consulted in the research process.

Table 1: Quality of life and wellbeing of autistic individuals with complex support or communication needs systematic review

Topic	Key findings	Key research gaps identified
Informants reporting on the quality of life and/or wellbeing	• In over one third of the studies, the quality of life and/or wellbeing of autistic people was reported by proxy informants (i.e., parents/caregivers, support staff or professionals) • Autistic informants were predominantly adults, without intellectual impairment or language impairment.	• High quality studies that include the voice of autistic people across the autism spectrum.
The methods used to measure quality of life and/or wellbeing	• The autistic community involvement in the research process was rarely reported • The majority of studies used questionnaire/survey measures to report on autistic people's quality of life and/or wellbeing • Over 60 different questionnaire/survey measures were used. These measures use different descriptors and domains of quality of life and/or wellbeing • Most questionnaire/survey measures were used in only one study making it difficult to compare findings on quality of life and/or wellbeing across studies • Adjustments or accommodations to support autistic informants were rarely identified.	• High quality studies that are co-produced with the autistic community • The identification of accessible methods to include the voice of autistic people across the autism spectrum • The development of reliable and relevant measures and tools to report on quality of life and/or wellbeing of autistic people from differing backgrounds and differing supports needs.
Whose quality of life is being reported on	• Less than half of the studies identified autistic people with co-occurring conditions • When co-occurring conditions were identified, these tended to be provided as a descriptor of the autistic people in the study and the impact of these co-occurring conditions on quality of life and/or wellbeing were rarely reported • Less than half of the studies reported on socio-economic status and ethnicity, factors that may be associated with quality of life and/or wellbeing • Autistic people with an intellectual impairment or language impairment were identified in less than one fifth of the studies and in some studies were specifically excluded • The functional ability of the autistic person was rarely identified.	• High quality studies reporting on the experiences of people across the autism spectrum • High quality studies exploring the impact of co-occurring conditions on autistic peoples' quality of life and/or wellbeing.
Quality of life and/or wellbeing	• Autistic people were rarely asked what they view as quality of life and/or wellbeing	• Autistic people's perspective on what is viewed as a good quality of life and/or wellbeing

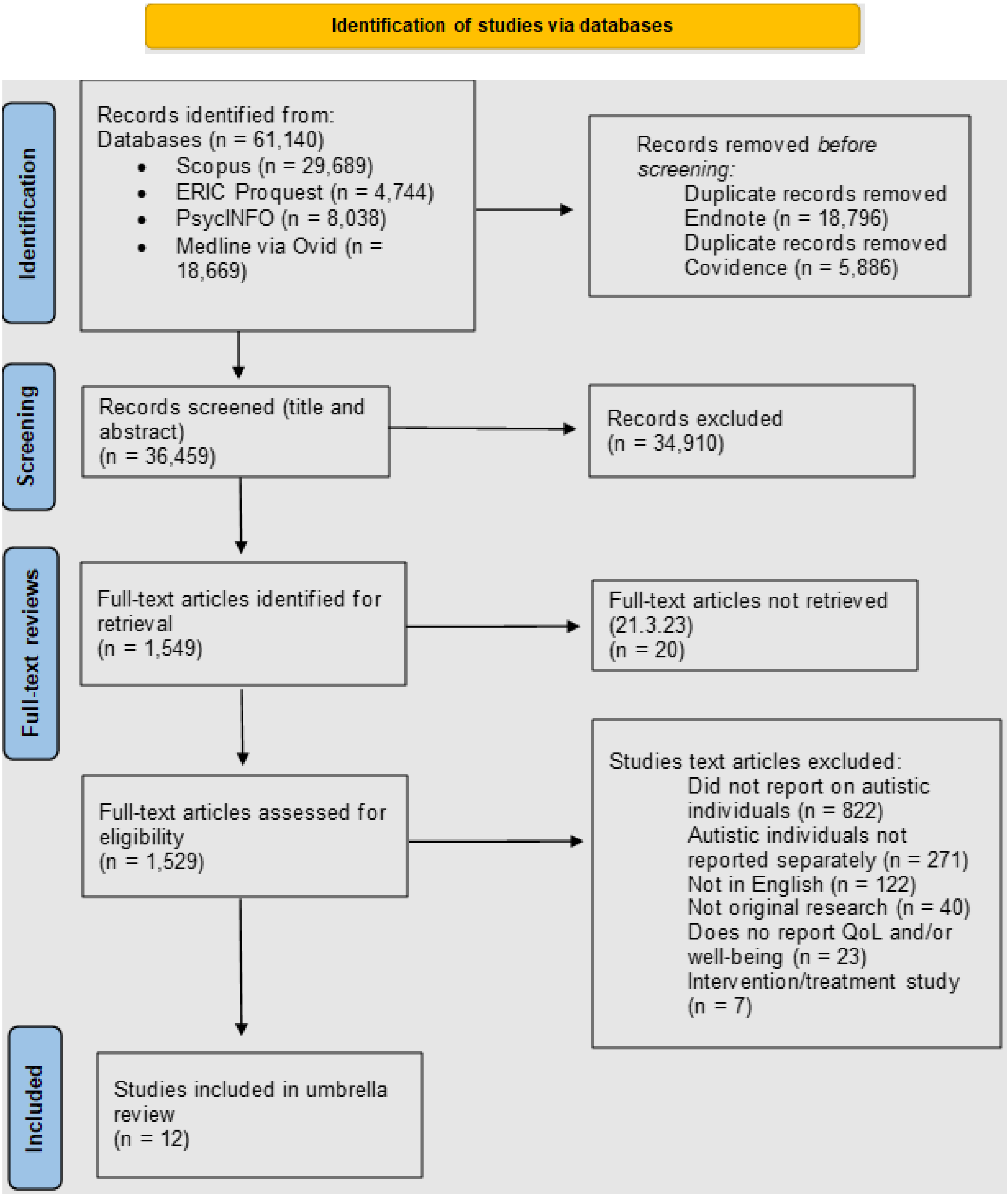
	• Autistic people are reported to have poorer quality of life and/or wellbeing than their non-autistic peers and this is reported from a young age • Comparative studies of autistic people’s quality of life and/or wellbeing was primarily based on diagnosis and seldom included the functional ability of the people • Personal and environmental factors can influence an autistic person’s quality of life and/or wellbeing • In the limited studies that reported on the impact of co-occurring conditions on an autistic person’s quality of life and/or wellbeing, mental health conditions was identified as a negative influence.	• Identification of personal factors that may influence an autistic person’s quality of life and/or wellbeing • Identification of environmental factors that can be modified to better support an autistic person’s quality of life and/or wellbeing.

Search terms

1.	Quality of life	Quality of life OR QoL OR health-related QoL OR HRQOL OR “health-related quality of life”
2.	Wellbeing	Well being OR wellbeing OR wellbeing
3.	Autism	autis* OR ASD OR Asperger* OR “pervasive developmental disorder” OR PDD* OR
4.	Umbrella terms to encompass co-occurring conditions	AAC OR augmentative and alternative communication OR complex care OR complex support OR complex need* OR complex communication OR communication deficit* OR delay* OR disabl* OR disabilit* OR disorder OR impair* OR non speak* OR nonspeak* OR non verbal OR nonverbal OR limited speech OR multimodal communicat* OR min* verbal OR retard* OR handicap OR neurodevelop* OR neurodiver* OR “medical condition”

Note. Terms are written in database code. Terms written in light blue were identified by autistic individuals.

PRISMA diagram



(Template from Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D et al. (2021). The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. *BMJ, 372* (71). doi: 10.1136/bmj.n71)

Appendix K: Physical health services

Appendix K-1: Content analysis categories

Question 1: What are three problems that autistic people experience when accessing, or trying to access, physical health care services?

Rank	Problems experienced by autistic people in relation to physical health services and sample quotes from responses	% of all respondents who stated this issue
1	**Staff in healthcare settings (providers and administrative staff) have a poor understanding or knowledge of autism, how it presents in different people or contexts and how it impacts the experience of healthcare settings.** (e.g., outdated knowledge of autism; lack of knowledge of how autism impacts the experience of healthcare settings) *"There is no indication at any GP or Health Care service that I have seen that they either specialise in or are experienced and trained to help autistic people. GP's and other health professionals do not know how to deal with autistic people."* (ID 915)	23%
2	**Long waiting lists to access physical health services** (e.g., long waiting time to access diagnostic, generalised and specialised services) *"Appointment waitlists are getting so long that by the time we get in, the problem is too far gone, already fixed, or we just don't want to go anymore because they don't care about us so why should we?"* (ID 153) *"There is nothing available in the regions. Everything is booked out for 12+ months."* (ID 570)	23%
3	**Health professionals' reluctance to adapt practices or provide accommodations/supports for autistic individuals** (e.g., inflexibility, one-size-fits-all, lack of neurodiversity-affirming care) *"Hospitals do not accommodate for the needs of people with autism. Quote from a hospital employee which identifies as disability friendly and has a disability liaison officer, 'they just have to suck it up'."* (ID 1172)	19%
4	**The sensory elements of physical health services or settings (including waiting rooms and emergency departments) are not supportive for autistic people, sometimes leading to sensory overwhelm.** (e.g., crowded, bright and noisy waiting rooms) *"Attending doctors' appointments is difficult. Waiting rooms are a sensory nightmare. [We are] often left waiting for a long time for appointments in waiting rooms then my daughter is over stimulated by the time her appointment is due to start, leading to erratic behaviour and meltdowns."* (ID 30) *"Hospitals are sensory nightmares. I went through chemotherapy for a year in sensory agony and no-one thought to turn off the fluorescent lights."* (ID 1163)	19%

5	**Physical healthcare providers dismissing or not believing the reports of autistic people or their family members (including not believing a person is autistic).** (e.g., dismissing symptoms or requests) *"They don't listen when we speak. If we say we are hurting, they think we are lying."* (ID 935) *"My diagnosis of autism is commonly ignored, minimised or dismissed. I am then either judged as a liar, fraud or a difficult patient or I get spoken to as if I have intellectual disability as well."* (ID 1436)	16%
6	**Differences or difficulties with communication, including autistic people experiencing challenges with describing their experiences, autistic people having to frequently repeat their descriptions to providers, and physical health providers not presenting information in a way that is accessible to autistic people.** *"They are worried about having to talk about their feelings. This is hard to articulate."* (ID 255)	16%
7	**Lack of health professionals and services, and disparity based on location (i.e., regional and rural)** (e.g., limited number of allied health and medical professionals; no services for particular age group/gender) *"Not enough psychologists/Speech Pathologists/OT to assess for ASD. Not enough psychologists/Speech Pathologists/OT to treat/manage social skills, sensory overwhelm and anxiety for those with ASD"* (ID 477)	14%
8	**Services are too expensive to access** *"It literally costs thousands every year. Even the reports to access the NDIS cost us over $10K combined (2 children). How do poor families access NDIS reports and ongoing medical care? I'm guessing many just miss out."* (ID 1112)	15%
9	**Difficulties with the process to access and physically attend health services** (e.g., organising and understanding forms, service availability/options, paperwork and appointments; transport) *"The amount of paperwork and hoops that the autistic person needs to successfully navigate in order to get help discourages people from trying."* (ID 195)	12%
10	**Adjustments or accommodations not offered, or system not taking into account needs or preferences of autistic people.** (e.g., appointments or therapies not autism-friendly; options for appointments [telehealth or in person]; and the process of arranging appointments) *"Everything requires a phone call - that's just not accessible for most autistic or neurodivergent people."* (ID 1494)	12%
11	**Concerns about professional's therapeutic skills** (e.g., lack of patience, empathy, care or understanding; mistreatment) *"Gaslighting from doctors and specialists who have no understanding of neurodiversity. It just doesn't feel safe."* (ID 955) *"My child is touch sensitive. Sometimes even a little protest make doctors frustrated and annoyed as well."* (ID 1432)	11%

12	**Lack of knowledge on atypical presentations (including pain and masking) and treatment of health problems in autistic people** *“Doctors having no understanding that just because someone isn't expressing a typical pain response it doesn't mean that they're not in pain”* (ID 105)	10%
13	**Challenges accessing sufficient funding to support physical health** (e.g., Medicare support; bulk-billing services; NDIS funding) *“I don't earn a lot of money so can't afford many health care services. I'm diagnosed Level 1 and my friends diagnosed with Level 2 & Level 3 have greater support options when it comes to healthcare.”* (ID 291) *“Some have to jump through hoops to prove their "disability" to access NDIS.”* (ID 1095)	10%
14	**Anxiety, stress or fear about accessing or trusting services** (e.g., refusal and/or distress to access support; past trauma; and negative experiences) *“Fear of being able to articulate their condition. Fear of crowded medical [clinics] and children making loud noises. [Fear] of having to speak with others. [Fear] of being not sick enough. [Fear] of being in a room with other sick people. Fear of the unknown when going to the doctor and no one to assist or go with them when unwell. Being unable to see the same doctor, so they put off seeing a strange doctor they have not met.”* (ID 171) *“Trauma involved in accessing medical support (eg. going to hospital) or getting an injection from medical professionals who are not adequately trained.”* (ID 526)	9%
15	**Poor clinical decisions** (e.g., misdiagnosing; reactive not preventative focus) *“15 years ago I was misdiagnosed with a mental health condition and put on medication that severely impacted my quality of life and ability to function but it [stabilised] my anxiety so that was acceptable to them. I lost my career. I lost my ability to work more than 25 hours a week. I lost my quality of life. I felt like a repeated failure.”* (ID 361)	8%
16	**Lack of autism-specific/ experienced service providers and specialists** (e.g., lack of health care professionals knowledgeable about autism; lack of autism specialists) *“Availability of appointments with health care professionals who have expertise in adult autism”* (ID 379) *“Lack of Specialists to meet the early needs of children on the Spectrum to allow them to progress to their potential”* (ID 1208)	8%
17	**Autistic characteristics and co-occurring conditions impacting access/use of services** (e.g., executive functioning skills; interoception) *“Often poor interoception and alexithymia is part of the autistic experience. Being aware of [internal] senses, and describing emotions can be a barrier. There can also be hypo or hyper sensitivity to pain. This can present major barriers in recognising when something is serious enough to require medical attention, and describing the pain sensations in terms of sensation and location accurately.”* (ID 602)	5%

Question 2: What do you think is causing these problems?

Rank	Factors causing the problems experienced by autistic people in relation to accessing physical health services and sample quotes from responses	% of all respondents who stated this issue
1	**Lack of/lack of funding for autism education, training, and upskilling of physical healthcare professionals** (e.g., lack of training within undergraduate and postgraduate level; insufficient on-going professional development and autistic-led training) *"There is also little to no training about Autistic people in most standard Health training. As an OT we did one lecture in one subject once. There are still lots of old myths/stigma in the general medical and allied health fields."* (ID 762)	26%
2	**Staff in healthcare settings (including administrative settings) have a lack of knowledge or understanding of autism/neurodiversity, the diversity of presentations, and how autism or other neurodivergence may impact physical health needs or symptoms (e.g., pain)** (e.g., lack of understanding individual needs; lack of understanding of autism; outdated knowledge) *"Their knowledge of autism is based on dated young male stereotypes from a particular part of the spectrum. Health care services know little current information about older, late diagnosed autistic women like me. They have no concept of the depth of trauma caused by being an undiagnosed autistic women living in a neurotypical world for 60 years and generally think I'm a sook and take none of my physical medical issues seriously."* (ID 1436)	24%
3	**Lack of funding/resources and/or difficulty accessing these supports (including the high costs of healthcare)** *"Less doctors are bulk-billing these days, so autistic (as well as neurotypical) people are not seeking medical help when they need it." (ID 1212)"*	23%
4	**Insufficient number of available healthcare professionals** (e.g., lack of professionals entering the field; lack of staff retention and incentives; a lack of university placements to train new professionals) "*Not enough allied health professionals available to be responsive. Since the introduction of NDIS people with a plan expect/are entitled to regular allied health intervention [so] it is hard for the moral allied health professional to encourage them to have a break from services as they want to keep seeing the same professional - these professionals aren't able to take on any new clients."* (ID 702)	17%
5	**Healthcare professionals demonstrating a lack of understanding, empathy, patience, care and acceptance for autistic people** (e.g., professionals showing discrimination and stereotyping of autism) "*Egos - people just don't care, and don't the time to understand, or WANT to get to the bottom of the issue, to actually then offer any real assistance."* (ID 147) *"Discrimination. You are treated like damaged goods. You are considered not worth saving. Even told you are the responsibility of DHHS. You are particularly devalued if you are autistic, nonverbal and have cognitive delays."* (ID 878)	10%

6	**Neurotypical/majority needs prioritised, ableism, and lack of neurodiversity-affirming practice** *"Because people expect everyone to look around and behave like everyone else… ASD are not typical and for the majority of lazy humans makes them too much effort. It is easy when everyone is the same."* (ID 469)	10%
7	**Lack of government support and guidance** (e.g., a lack of autism-specific research; lack of guidelines/policy; increased red tape and bureaucracy) *"Stronger rules, regulations and ethics needs to be implemented to eradicate the way funding is brutally misappropriated by physicians and service providers."* (ID 515)	10%
8	**A system with overwhelmed and overworked staff, time pressures and insufficient resources** (e.g., being rushed; no time for extra accommodations) "*Clinical staff are too busy and the health system overloaded to meet the sometimes complex health needs of an autistic person."* (ID 859)	9%
9	**Demand for health system exceeds supply, including increase in the prevalence of autism diagnoses and an increase in healthcare needs** *"The medical system is so swamped, sometimes I think they make it hard on purpose because they want fewer patients!"* (ID 479) *"The health system is under great strain and is not able to keep up with increasing physical health needs in GP clinics and hospitals, let alone other more specialist services"* (ID 1154)	8%
10	**Insufficient number of professionals or services with an interest/expertise in autism** (e.g., a lack of autistic professionals or those with lived experience; a lack of specialists in rural areas) *"A number of graduate therapists are working for NDIS service providers with people who require skill[ed] professionals but they are not adequately experienced or trained which is a disadvantage to the Autistic person."* (ID 1006)	8%
11	**The sensory elements of physical health services or settings (including waiting rooms and emergency departments) are overwhelming** (e.g., lighting and noise; physical layouts are poorly planning) "*Limited understanding of needs when building hospitals - accessibility isn't just someone in a wheelchair."* (ID 85) *"The hospital has a one size fits all building, no calming room, quiet area etc. Even the MCG has a calming room, but not our hospitals."* (ID 1172)	7%
12	**Health professionals' reluctance to adapt practices or provide accommodations/supports for autistic individuals or to see autistic clients** (e.g., inflexibility; refusal to see autistic clients) *"Sticking to old ways (there has always been just one waiting room for everyone)"* (ID 895) *"Clinicians seeing autism as too hard to work with so will avoid or refer on"* (ID 956)	6%

13	**Lack of communication accommodations** (e.g., booking and therapy options; language used; and non-verbal alternatives) *"Diagnosis and or next steps with regard to our health should be communicated clearly (step by step) in written or other form e.g., links to resources/ videos etc."* (ID 287) *"Lack of online booking - some GPs have online booking but I'm yet to find a specialist who offers it."* (ID 1110)	6%
14	**Lack of individual supports and accommodations** (e.g., lack of knowledge of accommodations) *"Lack of allowances being made as a standard inclusion in healthcare e.g. lighting changes, quieter rooms, sensory needs met, communication changes between professionals and patient etc"* (ID 75) *"Doctors and dentists will assume you are neurotypical. They do not ask or offer you any adjustments to their usual clinic practices (such as providing ear-buds at the dentist, or a stress ball/squeezy)"* (ID 204)	6%
15	**Systems are complex to access and there is a lack of support, resources and/or education to access health services** (e.g., absence of advocates; difficulty with transport) *"Lack of support for some autistic people to organise appointments, plan, problem solve etc to be able to see healthcare professionals"* (ID 535) *"Lack of education [provided] to them about help available, mainly just education to their parents or care-givers. There are Access Support services but very limited and not many people know about that"* (ID 667)	6%
16	**Communication, processing, and social interaction differences and/or difficulties** (e.g., processing issues; having to repeat information) *"I think it is part of how we communicate differently. You go to an appointment, the build up causes anxiety, you go there and there is social interactions with the [reception] staff that you need to rehearse [before] you go to, plan out motor movements and scripts, then you sit in the waiting room which is often overwhelming from a sensory perspective, then you are called into the consultation room, where the conversation doesn't go to script, your ability to communicate authentically goes off line, you end up answering questions by rote and don't really get to explain your problem to the detailed level you need to"* (ID 164)	5%
17	**Dismissing or excluding an autistic person or their family** (e.g., lack of questioning; ignoring symptoms and health concerns) *"Doctors being ableist and being quick to dismiss patient reports of discomfort. Being encouraged to ignore discomfort and pain growing up, leading to interoception issues."* (ID 1258) *"Not listening to the person with Autism's parents/carers/guardians and dismissing their concerns until it becomes a severe medical emergency or in some cases worse. Not explaining or not properly explaining what the diagnosis is and what the course of treatment is, how it works and what it should do."* (ID 1351)	5%

Question 3: What do you think could prevent or reduce these problems?

Rank	Factors that could prevent or reduce the problems experienced by autistic people in relation to accessing physical health services and sample quotes from responses	% of all respondents who stated this issue
1	**Increase (access to) education, training, and upskilling programs for healthcare professionals and administrative staff about autism, symptoms, and health impacts** (e.g., mandatory onboarding; autistic informed/delivered training; and university level training) *"There needs to be greater education about Autism for everyone working in physical healthcare services settings, and this education needs to be designed or co-designed with Autistic people."* (ID 290)	45%
2	**Increase the number of healthcare professionals and health services available.** (e.g., through incentives to increase rural/regional service; broadening scope of practice for health professionals) *"Train more doctors. Make it easier to transition to medicine later in life (e.g., scientists with PhD/pharmacists/vets could do a specialised MD training to build up the workforce."* (ID 578) "*Incentivising healthcare professions such as speech and occupational therapy*." (ID 1128)	21%
3	**Increase funding/resources and/or affordability of health services across the lifespan** (e.g., increasing access to funding; increasing bulk-billing services; reviewing funding systems such as NDIS) "*We need funding for medical expenses. NDIS won't cover my medical conditions, even though they are known to be linked to my neurodivergence. I am not a list of diagnoses with symptoms that can be easily categorised, I am a whole person and everything interconnects."* (ID 70) "*Flexibility in the Medicare funding system so that autistic patients had the capacity to access health services in the manner most suited to their needs."* (ID 1149)	19%
4	**Government reform, support, and guidance** (e.g., investment in research and services; guidelines, policy and regulations) "*Inclusion of autism in policy, guidelines and pathways so that autism is considered at all levels of health service system."* (ID 1068) "*Looking at how policy and practice is not meshing and figuring out to streamline this more effectively, so it meets the needs of autistic individuals more effectively."* (ID 1463)	14%
5	**Increase access and use of physical healthcare services for autistic people and their families through the provision of accommodations, flexible access options, and supports** (e.g., increased flexibility; and increased access to supports) "*An autistic person may appreciate being first to be seen (or sometimes last) - quieter, less people. [Having] a person at the front door who can assist others [with] directions, wheelchair, toy, drink etc. Someone who has a general understanding and helpful nature. This person might wear the same uniform, apron etc each day and is easy to identify."* (ID 452)	14%

6	**Increase communication options to improve access to healthcare and access to information about healthcare** (e.g., web-based booking systems; text-based communication; opting in or out of telehealth [i.e., not assuming it is preferred or unpreferred]) *“It should be mandatory that Autistic patients be able to communicate with clinics and healthcare professionals in ways that they prefer. No-one would ask a blind person to read a form, after all.”* (ID 290) *“Always have an online booking system for all health care services. This should be mandatory due to the fact some autistic people are not getting the health care they require or delaying accessing health care due to having to call for an appointment. In this technological age, this is a very easy solution to this problem.”* (ID 873)	12%
7	**Enhance the therapeutic skills and awareness of healthcare professionals to support their work with autistic clients** (e.g., acceptance; showing empathy and patience) *“More education and training on ND-affirming practices for all health professionals. The training needs to be affordable and accessible (e.g. online, self-paced as well as in-person) and is provided by health professionals who are ND.”* (ID 385)	11%
8	**Create sensory-friendly physical health services or settings, including training to inform healthcare professionals of how overwhelming these environments can be for autistic people and the impact this may have on their appointment** (e.g., create sensory friendly waiting rooms and emergency departments) “*More sensory friendly design choices (reduced lighting, quieter medical device notification systems) and accommodations (sensory friendly/quiet spaces…) considered for autistic patients.”* (ID 1051)	9%
9	**Actively employ, consult and collaborate with neurodivergent practitioners, support workers, advocates, and those in leadership/decision-making roles** (e.g., consult with autistic people when designing or developing services; services actively employing neurodivergent practitioners, support workers, advocates) *“Co-design with autistic people so needs are recognised and responded to in planning, implementation and delivery of services Service reviews by autistic people, to guide change or recognise achievements*.” (ID 677) “*Have more autistic doctors and nurses (medical professionals), and more autistic people include on the boards of hospitals and health services.”* (ID 935)	8%
10	**Provide support and education to individuals and families to improve health experiences and access** (e.g., teaching skills to autistic individuals; having support workers and advocates available; preparing autistic individuals for healthcare visits) “*Where possible provide resources to prepare autistic people for procedures that may be overwhelming, such as blood collection, having a cannula put in, x-rays, CT, MRI, Mammograms etc. these resources could be written in consultation with autistic people*.” (ID 1322)	8%

11	**Listen, validate, and take concerns of autistic individuals and their families/carers seriously** (e.g., asking questions; working in partnership with clients) *“Really listening to autistic people and what they are saying and asking more careful questions to ensure problems are identified (eg maybe take that xray even if [the] person says their broken looking arm doesn't hurt much)”* (ID 187) *“Ask permission before touching a patient…and check for understanding. [Do] not disregard autistic [persons’] experiences even if it seems far fetched. [Be] curious!”* (ID 1550)	6%
12	**Increase continuity of care, coordination of care and communication between service providers and care teams** (e.g., development of health plans; providing referral pathways) *“Case conferences and coordination between the "Team" that manages individual cases.”* (ID 689) *“Have a system that allows for ONE accessible record that can be accessed by allied health, [GPs,] specialists, and emergency services and departments. So anyone who has to treat an Autistic person can have fast access to the person's history.”* (ID 1394)	5%

Question 4: What is working well, or has worked well, in relation to autistic people accessing mental health services?

Rank	What is working well, or has worked well, in relation to autistic people accessing mental health services and sample quote from responses	% of all respondents who stated this issue
1	**Nothing/not a lot** *"Nothing. Everything is designed to be difficult and you give up before you achieve what you set out to most of the time"* (ID 88) *"Nothing about the current system is working well. Nothing at all."* (ID 318)	22%
2	**When you find the right physical health provider for you, who was often described as knowledgeable about autism, understanding, caring, patient, and non-judgemental** *"It's luck of the draw. Every now and then I come across someone who is gentle, understanding and genuinely wants to know my needs or my children's needs."* (ID 1081) *"I once had a nurse get angry at me for having a meltdown within hours after the birth of my baby! But…one nurse pulled me aside to tell me she understands, her nephew is autistic. This helped. People in the industry expressing their understanding from a personal perspective (in an appropriate and professional way!) works wonders to help me feel safe and supported."* (ID 1251)	18%
3	**When NDIS plans and funding are approved for health supports** (e.g., helpful NDIS coordinators can improve access to services; reduces financial burden on families) *"NDIS has been helpful to support access to allied health services for my son"* (ID 384)	14%
4	**When healthcare providers proactively ask about and provide alternative/flexible access, accommodations and/or support for autistic individuals.** (e.g., longer appointments; more flexibility with appointments; support people attending; home visits) *"Being allowed advocates with them even as adults [and] longer consultation times awareness and acceptance."* (ID 773) *"I have only had one positive experience and the hospital worked with us and allowed the assistance dog into pre-op as well."* (ID 1061)	13%
5	**When supports are provided that prepare autistic individuals for accessing healthcare services or initiatives/supports that help access to health services** (e.g., preparation resources for autistic individuals; access to support workers; educated carers/families; supports for families) *"Visiting the dentist often for very short appointments to get better at opening the mouth for viewing and touching the teeth."* (ID 942) *"Support workers funded through the NDIS to assist with access, physical access, and mental preparation and capacity building for the appointment."* (ID 998)	10%
6	**When there are increased communication options to improve access, and information about,** (e.g., web-based booking systems; option of telehealth; non-verbal communication options) *"Telehealth appointments meant I was able to speak to a GP and turn my life around."* (ID 154)	10%

	“I have had the option at a doctors of online booking with a comment section so that I could put in the reason that I was making the appointment. It was really helpful because it meant that when I got there the doctor already had the reason for my visit in front of them. I didn't have to try and remember all the details and then get them across while I was stressed and overwhelmed.” (ID 323)	
7	**Healthcare providers having an awareness and knowledge of autism, the characteristics of autism (including sensory needs) and different presentations (including the presentation of autism in women or girls)** *“There are more practitioners now who understand autism and women. I had to join a long waiting list, but I've found a psychologist and a GP who are great.”* (ID 291) *“Many autistic people have found a space free from judgement where they can unmask and work through their needs, values, cognitions and behaviour with a skilled practitioner.”* (ID 808)	9%
8	**When there is an increased access to health professionals and services** (e.g., autistic led services; services that have expertise in autism) *“Having dedicated autism services, like the dental clinic at Queen Elizabeth II Hospital in Brisbane. Clinicians in such services consistently work within the autism context and such services develop better processes for providing tailored health care for Autistic people.”* (ID 1362)	8%
9	**When there is continuity of care and continuity of information across providers.** (e.g., through collaborative health teams; building relationships; individual care plans; accessible health information; health passports) *“When medical professionals are well informed about an Autistic person's needs e.g. with written information, there is often increased choices that enable a greater sense of control and predictability and procedures are less traumatic.”* (ID 354).	7%
10	**When providers ask questions and listen to autistic people and/or their family members, and include autistic individuals and their families in healthcare decisions** *“When people have listened and you are treated with respect... When you are asked "How does that look like for you[?]"...Working together, and realising that if things aren't working out then you need to change approach, not just withdraw service.”* (ID 495) *“An A&E doctor who spoke directly to my daughter. He explained what he wanted to do e.g. check [heart] rate, asked permission before using stethoscope. he described what was involved in inserting a cannula and why he wanted to do it, asked permission and allowed her to feel each implement before he used it. My daughter is 19 and this was the first positive interaction she has ever had with a health professional. he was kind yet matter of fact without being condescending. She left feeling heard and empowered.”* (ID 1550)	7%
11	**When health spaces are comfortable and sensory-friendly** (e.g., calm waiting rooms; alternative meeting spaces; virtual reality; dim lights) *“We have been given our own hospital room when we have to attend hospital to make things easier for my son.”* (ID 222) *“More sensory friendly design choices (reduced lighting, quieter medical device notification systems)”* (ID 1051)	6%
12	**Recent shift towards neuro-affirming and strength-based practice** (e.g., focussing on the social model of health) *“A shift to neurodivergent affirming language and practises (e.g., steering away from goals such as "eye contact")”* (ID 691)	6%

13	**When healthcare services are affordable and there is access to funding (beyond NDIS)** (e.g., Medicare rebates; bulkbilling; and Health Care cards) *“Bulk billing and concession cards meant seeing the GP was affordable.”* (ID 162) *“Medicare - may it stay, may it grow, may it support people even more in the future. We all pay for it including autistic people and their families, so all of us should benefit from accessing it equitably.”* (ID 1512)	5%
14	**Increased and comprehensive diagnosis of autism and data provided to inform support** (e.g., early diagnosis; comprehensive assessments) *“Comprehensive assessments and appropriate feedback which enable autistic people and their families to understand their situation and advocate for supports”* (ID 460) *“Maternal and Child Health SACS screening in Victoria is an excellent tool to identify children at risk and refer for early intervention”* (ID 661)	5%
15	**Increased delivery of autism training and education to health professionals** (e.g., autistic informed/delivered training; university education) *“[Specialist] trained clinicians- in every field the simplistic level of understanding and small level of accommodation can reduce anxiety, ptsd, negative associations and improve quality of life”* (ID 901) *“Employers looking at how to provide training to staff to improve the understanding of those who need to access the service.”* (ID 1318)	5%

Appendix K-2: Umbrella review search terms

The following search terms were used for the respective databases:

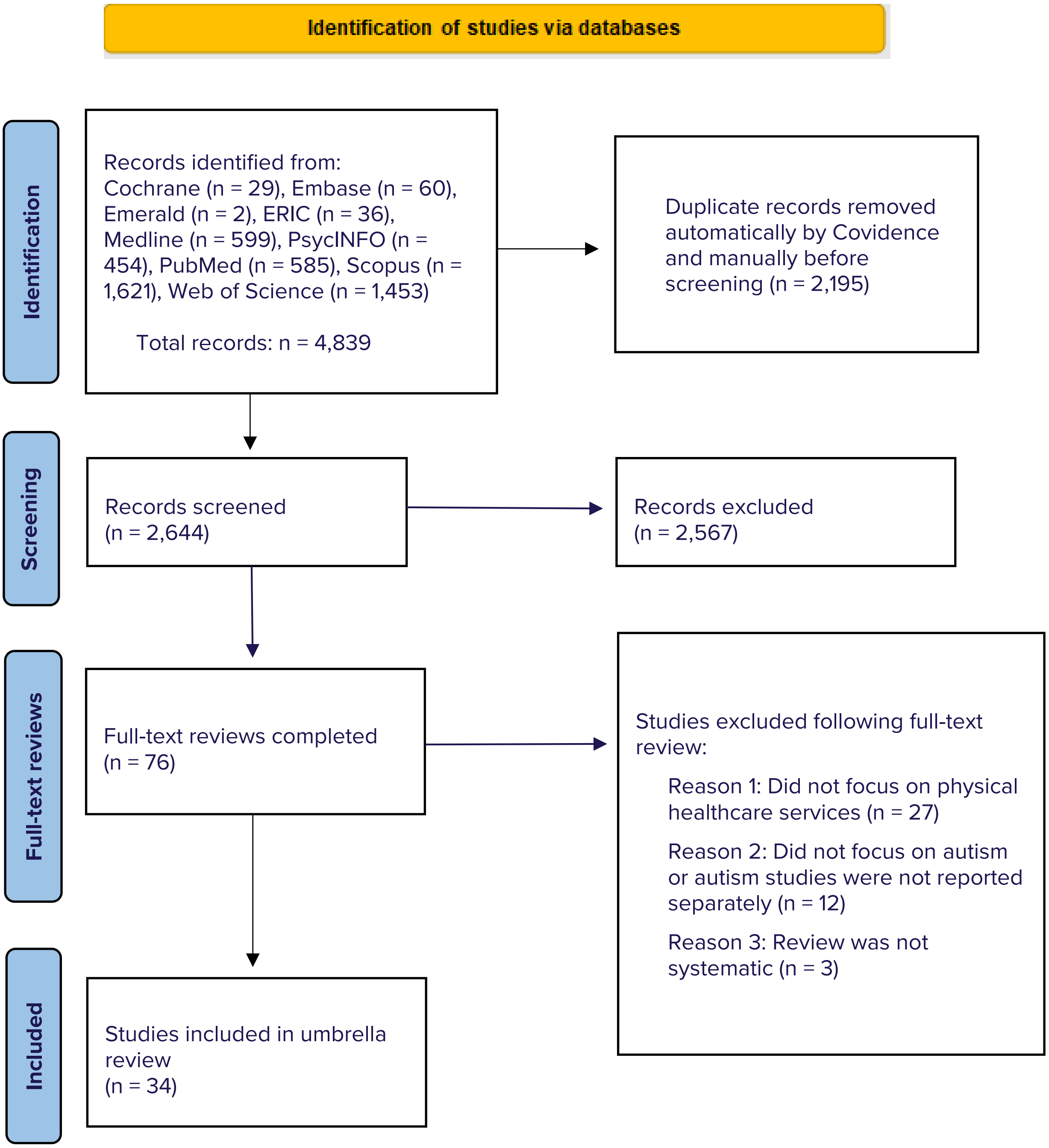
Cochrane, Embase, Emerald, ERIC, Medline, PsycINFO, PubMed, Web of Science

(autis* OR ASD OR ASC OR Asperger* OR pervasive developmental disorder OR PDD) AND (healthcare OR health care OR physical health* OR medical* OR health system OR primary care OR secondary care OR tertiary care OR hospital* OR ward OR clinic OR general practi* OR GP OR doctor OR nurs* OR surgeon* OR health professional* OR practitioner* OR paediatrician* OR physician* OR medical staff OR dent* OR medical OR emergency room* OR casualty OR emergency department OR emergency service OR emergency medicine OR paramed* OR health service* OR telehealth OR telemedicine OR allied health* OR therapist* OR NDIS OR National Disability Insurance* OR rehab* OR occupational therap* OR speech therap* OR physical therapy* OR speech patholog*) AND (systematic review* OR scoping review OR narrative review OR systematic literature review* OR systematic quantitative literature review OR evidence synthes* OR meta-analy* OR meta-regression*)

Scopus

(autis* OR ASD OR ASC OR Asperger* OR “pervasive developmental disorder” OR PDD) AND (healthcare OR “health care” OR “physical health*” OR medical* OR “health system” OR “primary care” OR “secondary care” OR “tertiary care” OR hospital* OR ward OR clinic OR “general practi*” OR GP OR doctor OR nurs* OR surgeon* OR “health professional*” OR practitioner* OR paediatrician* OR physician* OR “medical staff” OR dent* OR medical OR “emergency room*” OR casualty OR “emergency department” OR “emergency service” OR “emergency medicine” OR paramed* OR “health service*” OR telehealth OR telemedicine OR “allied health*” OR therapist* OR NDIS OR “National Disability Insurance*” OR rehab* OR “occupational therap*” OR “speech therap*” OR “physical therapy*” OR “speech patholog*”) AND (“systematic review*” OR “scoping review” OR “narrative review” OR “systematic literature review*” OR “systematic quantitative literature review” OR “evidence synthes*” OR meta-analy* OR meta-regression*)

Appendix K-3: PRISMA diagram



Records identified from: Cochrane (n = 29), Embase (n = 60), Emerald (n = 2), ERIC (n = 36), Medline (n = 599), PsycINFO (n = 454), PubMed (n = 585), Scopus (n = 1,621), Web of Science (n = 1,453)

Total records: n = 4,839

Duplicate records removed automatically by Covidence and manually before screening (n = 2,195)

Records screened (n = 2,644)

Records excluded (n = 2,567)

Full-text reviews completed (n = 76)

Studies excluded following full-text review:

Reason 1: Did not focus on physical healthcare services (n = 27)

Reason 2: Did not focus on autism or autism studies were not reported separately (n = 12)

Reason 3: Review was not systematic (n = 3)

Studies included in umbrella review (n = 34)

(Template from Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D et al. (2021). The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. *BMJ, 372* (71). doi: 10.1136/bmj.n71)

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Appendix K-5: Policy search strategy

Step 1	• Physical Healthcare sectors were identified using the Australian Federal Department of Health and Aged Care website: https://www.health.gov.au/about-us/the-australian-health-system • Sectors were cross-checked and sub-sectors added, where relevant, using the Australian Institute of Health and Welfare (AIHW) and Australian Healthcare Practitioner Regulation Agency (Ahpra) websites: https://www.aihw.gov.au/reports/australias-health/health-system-overview and https://www.ahpra.gov.au/Registration/Registers-of-Practitioners/Professions-and-Divisions.aspx
Step 2	• Key documents (including policies, guidelines, and statements) relating to the national sectors and sub-sectors identified were sourced from the above websites and other Federal Department websites (where appropriate). • Key documents were searched for the terms autis* and disab* and relevant sections were extracted. Documents that did not mention autism and/or disability were also highlighted.
Step 3	• The physical healthcare sectors were then searched for on each State and Territory health (as well as other relevant government department or professional body) websites. • Key documents (including policies, guidelines, and statements) were sourced. Key documents were searched for the terms autis* and disab* and relevant sections were extracted. Documents that did not mention autism and/or disability were highlighted as well as if national policies, strategies or bodies governed the respective State or Territory healthcare sectors or approaches.
Step 4	• A general Google search was then conducted to ensure that key documents had not been missed during Steps 1-3.

Our values

Inclusion
Valuing lived experience

Innovation
Solutions for long term challenges

Evidence
Truth in practice

Independence
Integrity through autonomy

Cooperation
Capturing opportunities together

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