Caregiver Experiences and Systemic Barriers to Early Autism Diagnosis in South Australia: A Mixed-Methods Study

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Abstract

Purpose: Across Australia's eight states and territories, families continue to experience prolonged and inequitable waits for autism diagnosis despite national reforms promoting identification from two years of age. Although national research identifies barriers related to cost, coordination, and service access, little is known about how these challenges manifest within individual jurisdictions undergoing distinct reform trajectories. South Australia provides one such case, implementing initiatives including the Office for Autism and the Inklings Early Identification Pilot. This study examined systemic barriers, caregiver experiences, initiative awareness, and confidence in collaborative diagnostic models.
Methods: A convergent mixed-methods design integrated survey data *(n=65)* and semi-structured interviews *(n=6)* with caregivers of children aged 2-6 years. Quantitative data were analysed descriptively, and qualitative data thematically using Braun and Clarke's (2006) framework. Triangulation identified convergence and divergence across datasets.
Results: Most caregivers were female (89%) and tertiary educated (72%). Despite early recognition of developmental differences, one-third reported delays exceeding 12 months. High out-of-pocket costs (74%), long wait times (68%), and limited service-navigation support (51%) were the most common barriers. Awareness of South Australian reforms was low (<40%), while confidence in allied-health-led collaborative models remained high.
Conclusions: Diagnostic fragmentation, high costs, and unclear professional authority continue to delay autism identification in South Australia. Findings underscore that system opacity, rather than parental capacity, remains the primary barrier. Clearer governance, subsidised early assessment, and embedded navigation roles are required to strengthen equitable diagnostic pathways within and across Australian jurisdictions. These findings provide early insight into priorities within South Australia's evolving reform environment.

Keywords

Autism diagnosis; caregiver experiences; mixed methods; health system barriers; South Australia; multidisciplinary collaboration.

Introduction

Autism spectrum disorder (ASD) is a lifelong neurodevelopmental condition defined by differences in social communication and interaction, alongside repetitive patterns of behaviour (American Psychiatric Association, 2022). In Australia, the average age of diagnosis remains between three and four years (Department of Social Services [DSS], 2025), despite contemporary evidence demonstrating that reliable identification is possible from two years of age (Zwaigenbaum et al., 2015). Earlier diagnosis is associated with timely intervention and improved developmental outcomes, including gains in communication, adaptive functioning, and social participation (Bent et al., 2015; Whitehouse et al., 2018).

In Australia, an autism diagnosis is guided by two complementary frameworks: the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5-TR), which defines clinical criteria, and the National Guideline for the Assessment and Diagnosis of Autism in Australia, developed by the Autism CRC. The National Guideline, approved by the National Health and Medical Research Council (NHMRC), recommends multidisciplinary, evidence-based assessments but remains non-binding, allowing states to interpret it differently.

In practice, autism diagnoses are usually made by paediatricians, psychiatrists, or clinical psychologists, supported by allied health input such as speech pathology and occupational therapy (Taylor et al., 2016; Bent et al., 2015). Typically, families begin by raising concerns with educators or a general practitioner (GP), who then provides referral to specialists, however, many families now bypass GP gatekeeping due to long waits or previous dismissal, initiating contact directly with private psychologists or speech pathologists, a trend increasingly documented in Australian diagnostic pathways (Bent et al., 2015; Gibbs et al., 2018).

Australian research repeatedly identifies long waits, high costs, and unclear referral pathways as key barriers to early diagnosis (Taylor et al., 2016; Ward et al., 2016; Whitehouse et al., 2018; Smith-Young et al., 2022; Boulton et al., 2024). Families describe fragmented pathways requiring them to act as de facto case managers, navigating disconnected services with little professional coordination (Evans et al., 2025). Despite these insights, comparatively fewer studies have examined how diagnostic governance and policy structures at national and state levels contribute to these challenges.

Previous studies have improved understanding of diagnostic access barriers but often focus on availability of clinicians and services rather than policy frameworks shaping access. For example, Taylor et al. (2016) identified substantial variation in clinician decision-making linked to inconsistent guidelines uptake, while Ward et al. (2016) and Smith-Young et al. (2022) highlighted financial and time constraints without exploring system-level governance reinforces these inequities. All three studies were conducted in Australia but did not evaluate the impact of emerging national reforms.

Evans et al. (2025) also noted weak interprofessional collaboration but did not evaluate whether reforms such as the National Guideline or National Disability Insurance Scheme (NDIS) improved coordination. The NDIS, introduced in 2013, being nationally rolled out by 2020, is Australia's national disability funding scheme, and access to supports requires diagnostic confirmation, making navigation of assessment pathways critical.

State-level variation continues to shape inequities in diagnostic age and process. Bent et al. (2015) found earlier diagnosis in Western Australia and New South Wales compared with other states, while highlighting families' experience of uncoordinated assessments lacking multidisciplinary input. Australia comprises six states and two territories, each with

distinct health, education, and disability governance structures, making jurisdictional differences important for international readers and contextualising state-based inequities.

Access to the NDIS depends on diagnostic confirmation, making awareness of the scheme a key determinant of families' navigation experiences (Smethurst et al., 2021). This study therefore also explored caregiver awareness of the NDIS and related South Australian initiatives, to understand how policy intentions align with lived diagnostic experiences. Awareness of recent state initiatives, rather than of established structures such as the NDIS, was expected to be lower due to their recent introduction.

National reforms such as the National Autism Strategy (DSS, 2025) aim to unify assessment and inclusion. In South Australia, the Office for Autism (2022), Autism Inclusion Teacher Initiative (2023), and Inklings Early Identification Pilot (2024 for Western Australia, 2025 for South Australia) mark steps toward coordinated early identification. The Office for Autism provides statewide policy leadership, the Autism Inclusion Teacher Initiative embeds autism-trained teachers into public schools, and the Inklings Pilot supports early developmental monitoring through child-health and early childhood services.

Beyond clinical pathways, early autism diagnosis can be understood as a structural and social determinant of health, shaping access to intervention, education, and disability funding across the life course (WHO, 2025). Australian and international work increasingly situates diagnostic delay and service fragmentation within broader patterns of health system inequity, whereby those with fewer resources or lower system familiarity shoulder heavier navigation burdens (Babalola et al., 2024; Bent et al., 2015; Hussain et al., 2023). Within this lens, governance arrangements, policy communication, and funding structures become central determinants of whether families can realise the benefits of early identification, rather than individual-level motivation or knowledge alone. Positioning autism diagnosis within this

structural frame emphasises the importance of examining jurisdiction-specific reforms, such as those in South Australia, for their potential to redress or entrench inequity.

Current Study

Australian research consistently demonstrates that families encounter long waits, high costs, and fragmented pathways when seeking an autism diagnosis for young children, even within systems that endorse early identification (Taylor et al., 2016; Ward et al., 2016; Smith-Young et al., 2022). More recent Australian studies further show that parents often shoulder the bulk of navigation, with uneven uptake of the National Guideline contributing to inconsistent assessment practices across states (Gibbs et al., 2019; Evans et al., 2025). Evidence also highlights jurisdictional variation with some states already introducing coordinated screening initiatives, while others rely heavily on private pathways, creating differential access to multidisciplinary assessment (Bent et al., 2015; Autism CRC, 2023). Despite these insights, little is known about how these systemic pressures manifest within South Australia, a state undergoing active reform through the Office for Autism, Autism Inclusion Teachers, and the Inklings Early Identification Pilot.

Against this background, this study explored equitable and timely access to autism diagnosis for South Australian children aged 2-6 years. Specifically, this study examined, (1) systemic and structural barriers to timely diagnosis, (2) caregiver experiences navigating pathways, (3) awareness and engagement with national and state initiatives, and (4) confidence in collaborative, multidisciplinary models. A convergent mixed-methods design was employed to integrate survey and interview data, capturing both the breadth of system-level patterns and the depth of caregiver experience.

Taken together, these national and state-specific patterns suggest clear expectations regarding barriers, initiative awareness, and collaborative preferences within South Australia. Based on these documented national patterns of cost, wait times, fragmented pathways, and the emerging role of allied-health collaboration, the following hypotheses were proposed: families would report prolonged wait times, financial strain, and inconsistent referral pathways, particularly among low-and middle-income or rural households. It was further anticipated that awareness of South Australia's recent reforms would be low due to their early stage of implementation, while support for multidisciplinary diagnostic models would be strong considering national calls for coordinated assessment. These hypotheses directly aligned with the study's aims, enabling a focused examination of systemic barriers, reform awareness, and preferences for collaborative diagnostic models within South Australia's evolving reform environment.

Methods

Ethics

Ethics approval was granted by the Flinders University Human Research Ethics Committee (HREC #8547). All participants received comprehensive written information regarding the study's purpose, procedures, risks, and confidentiality, and provided informed consent prior to participation in both the survey and interviews by either selecting the consent boxes to proceed and/ or accepting the invitation for interview. Verbal consent was also confirmed at the beginning of each interview.

Research Design

This study was guided by a constructivist epistemology, acknowledging that understanding and accessing autism diagnosis involves both structural systems and families'

lived realities (Creswell & Plano Clark, 2017; Vivanti & Messinger, 2021). This orientation aligns with qualitative traditions in autism research that emphasise the co-construction of meaning and the centrality of lived experience. Within this epistemological position, a convergent mixed-methods design was selected to capture both structural patterns and lived experiences of diagnostic access (Creswell & Plano Clark, 2017). Quantitative survey data offered a broad, policy-relevant overview of barriers, initiative awareness, and confidence in collaborative models, while qualitative interviews provided depth regarding how these factors played out across family, cultural, and geographic contexts. Similar designs have been used to evaluate models of autism assessment and service organisation, reflecting the need to integrate system-level indicators with family narratives when appraising equity and quality of care (Frakking et al., 2022; Gibbs et al., 2021). This approach is therefore well suited to understanding how South Australia's evolving reforms intersect with caregiver experiences in real time.

Design

A convergent parallel mixed-methods design (Creswell & Plano Clark, 2018) integrated quantitative and qualitative data collected concurrently. Survey and interview data were analysed independently and then merged during interpretation to capture both systemic trends and family experiences (Fetters et al., 2013) Merging involved a side-by-side comparison of quantitative and qualitative findings, identifying areas of convergence, complementarity, and divergence in relation to each research aim.

This approach allowed examination of barriers to timely and equitable autism diagnosis for South Australian children aged 2-6 years. Survey data identified systemic patterns, while interviews provided contextual depth. Interviews were conducted via Microsoft Teams, recorded, cross-checked for accuracy by the primary researcher against the

audio recording, and thematically analysed using Braun and Clarke's (2006) six-phase reflexive framework in NVivo (Release 1). The survey included of 26 questions (Appendix A), while interviews followed a semi-structured guide (Appendix B).

To our knowledge, this is the first mixed-methods study in Australia to explore autism diagnostic equity within South Australia's evolving reform context, aligning with the Social Determinants of Health (WHO, 2025), National Autism Strategy (DSS, 2025), National Guidelines (Autism CRC, 2018). This study explicitly situates autism diagnosis within broader structural and policy determinants, informed by national and state-level reforms.

Reflexivity statement

The primary researcher's dual role as a registered nurse and parent of a child within the autism context informed both professional and personal insight. This perspective enhanced empathy and interpretive depth, particularly regarding system navigation and family experience. This dual role was disclosed to participants at the beginning of each interview to support transparency and informed participation. Reflexivity was maintained through journalling, documentation of analytic decisions, and supervisory debriefing to ensure interpretations remained participant-driven (Berger, 2013; Nowell et al., 2017). Decisions regarding coding, theme refinement, and the integration of quantitative and qualitative findings were documented and reviewed with supervisors to minimise unchecked assumptions and to ensure that analytic claims remained grounded in the data rather than personal experience. This deliberate attention to reflexivity and oversight strengthens the credibility and trustworthiness of the study's interpretations.

Participants and recruitment

Participants were eligible to participate if they were English-speaking caregivers aged over 18, residing in South Australia, with a child aged 2-6 years awaiting or recently (<12 months) diagnosed. Recruitment occurred via social media, autism organisation distribution, and QR-code flyers. Recruitment involved unpaid social media, a paid distribution via a SA autism organisation, and QR-code flyers. Both unpaid and paid outreach approaches were used to maximise reach across metropolitan communities.

This survey was hosted on Qualtrics and accessible publicly. Interested participants provided consent for follow-up interviews through a separate Qualtrics survey to preserve anonymity. Interviews were scheduled and conducted online via Microsoft Teams.

Survey phase

Quantitative data were collected through a structured Qualtrics survey (Appendix 1) designed to capture demographics, referral pathways, perceived diagnostic barriers, awareness of national and SA autism initiatives, and caregiver confidence in collaborative diagnostic models. Participants could enter a draw for one of three $20 vouchers funded through the researchers Honour's stipend. The survey contained 26 questions, with additional items displayed conditionally through skip/display logic when relevant.

Interview phase

Semi-structured interviews (Appendix 2) were conducted, with participants who opted in through the separate Qualtrics consent survey. Participants reviewed the interview guide and consent materials, which were accessible for download prior to providing contact details and later re-sent during scheduling. Interviews explored families' diagnostic journeys,

perceptions of state and national initiatives, and views on collaborative models of diagnosis. Interviews lasted up to one hour, were audio-recorded using Microsoft Teams, automatically transcribed, and manually verified for accuracy. Participants received a $20 voucher, funded from the Honours stipend, in recognition of their contribution, upon transcript approval. All participants approved their transcripts, with one requesting minor wording clarifications.

Data storage and confidentiality

Surveys were anonymous, and participants who wished to opt-in to the voucher draw or interview, were invited to provide contact details. Audio recordings and verified transcripts were de-identified and stored securely on a password-protected Flinders OneDrive accessible only to the research team. Microsoft Teams recordings comprised combined audio-visual files, these, which were treated as a single recording, de-identified, and stored under the same secure conditions, with no visual material reported in dissemination to protect confidentiality.

Data analysis

Quantitative data

A three-step screening procedure addressed (1) incomplete responses across key survey items (Q4-Q-25), (2) potential duplicates or low-quality entries, and (3) completeness and face validity. Incomplete or low-quality responses identified through this process were removed prior to analysis, to maintain dataset credibility. Descriptive statistics summarised demographics and barriers; cross-tabulations explored sex-based patterns.

Qualitative data

Interview transcripts were analysed thematically using Braun and Clarke's (2006) six-phase reflexive thematic analysis: (1) familiarisation, (2) initial coding, (3) theme generation,

(4) reviewing themes, (5) defining and naming themes, and (6) reporting. Inductive coding was conducted in NVivo (Release 1) with iterative refinement of codes into subthemes aligned with the research aims. Analysis was performed by first author (SLH), in consultation with the supervisory team (LL, JA, MZ), to enhance analytic credibility, reflexive rigour, and interpretive transparency (Nowell et al., 2017). Thematic development was an active, interpretive process involving continual comparison, memo-writing, and reflexive discussion. Any amendments to early code structures or theme definitions were reviewed collaboratively with supervisors to ensure consistency and reflexive accountability.

Integration of data

Quantitative and qualitative findings were integrated at the interpretation (step 2) stage using a side-by-side display approach to identify convergence, complementarity, and divergence (Creswell & Plano Clark, 2018). This approach enabled a holistic understanding of diagnostic equity by linking systemic patterns with lived experience.

Results

The results are presented according to the two types of data collected, (1) quantitative survey results, and (2) qualitative interview findings, consistent with the convergent mixed methods design. This structure first outlines caregiver trends, followed by deeper exploration of lived experiences.

Quantitative survey data

Of a total of 204 survey responses, 65 *(n=65)* met inclusion criteria following the three-step screening procedure (31.9%). Responses were removed at either step of the screening procedure.

Participant and Child Characteristics

Table 1 presents the demographic characteristics of survey participants and their children. Survey participants were predominately female (*n=58; 89%)*, aged 30-39 years *(n=42; 64.6%)*. Educational attainment was high, with majority of the holding tertiary qualifications or higher *(n=47; 72.3%)*. Employment was primarily part-time *(n=25;38.46%)*, followed by 'other' (*n=17; 26.15%).*

Most children were male *(n=41; 63%)* with a large portion still being represented by children identified as female *(n=23; 35%)*. Developmental concerns were identified early, most before age two *(n=48; 74%),* yet one-third *(n=23;35%)* waited over 12 months for a formal diagnosis. Participants expressed notice of concerns from 6 months *(n=22;33.85%)* and two years *(n=22;33.85%).* Participants who had received a formal diagnosis (*n=34;52.31%)*, were closely represented to those who had not *(n=31;47.69%)*. Of the participants who had received a formal diagnosis, the majority reported waiting over 12 months from first concerns and formal diagnosis *(n=25;34.46%)*. Participants reflected the key professionals involved as predominately speech pathologists *(n=40;61.54%)*, followed by paediatricians (*n=33;50.77%)*, psychologists *(n=32;49.33%)*, and occupational therapists *(n=25;38.46%)*. Of the professionals involved, the less common one's were represented by general practitioners (*n=23;35.38%)*, social workers *(n=7;10.77%)* and nurse *(n=5;7.69%)*.

Table 1

Survey participant demographic characteristics and their children's *n=(65)*

Characteristic	**Category**	**N (%)**
Parent age group	20-29 years	11 (16.92%)

	30-39 years	39 (60.0%)
	40-49 years	13 (20.0%)
	50-59 years	1 (1.54%)
	Under 20 years	1 (1.54%)
Parent gender	Female	58 (89.2%)
	Male	6 (9.2%)
	Prefer not to say	1 (1.5%)
Highest education level of parent	Completed year 10 or below	5 (7.69%)
	Completed year 12 or equivalent	4 (6.15%)
	Certificate I or II	2 (3.08%)
	Certificate III or IV (e.g. TAFE/ trade)	13 (20.00%)
	Diploma or advanced diploma	13 (20.00%)
	Bachelor's degree (e.g. BN, LLB)	19 (29.23%)
	Graduate diploma/ certificate	1 (1.54%)
	Masters degree (e.g. Med. MA)	5 (7.69%)
	Doctoral degree (e.g. PhD, EdD)	2 (3.08%)
	Other	1 (1.54%)
Employment status of parent	Casual	3 (4.62%)
	Part-time	25 (38.46%)
	Full-time	16 (24.62%)
	Prefer not to say	4 (6.15%)
	Other	17 (26.15%)
Child gender	Male	41 (63.08%)
	Female	23 (35.38%)
	Prefer not to say	1 (1.54%)
Age of child when concerns first noticed	6-12 months	22 (33.85%)
	1-2 years	22 (33.85%)
	2-4 years	17 (26.15%)
	4-6 years	2 (3.08%)
	other	2 (3.08%)

Which services or professionals were involved in your child's diagnosis or assessment? **	Paediatrician	33 (50.77%)
	Psychologist	32 (49.33%)
	Speech pathologist	40 (61.54%)
	Occupational therapist	25 (38.46%)
	Social worker	7 (10.77%)
	General practitioner	23 (35.38%)
	Nurse	5 (7.69%)
	Other	11 (16.92%)
Received a diagnosis	Yes	34 (52.31%)
	No	31 (47.69%)
Age of child at diagnosis* (31 not represented as not diagnosed)	2 years old	9 (13.85%)
	3 years old	7 (10.77%)
	4 years old	5 (7.69%)
	5 years old	4 (6.15%)
	6 years old	8 (12.31%)
	Other	1 (1.54%)
Time between concerns first noticed and diagnosis* (31 not represented as not diagnosed)	1-2 months	1 (1.54%)
	6-12 months	4 (6.15%)
	Over 12 months	25 (34.46%)
	Other	1 (1.54%)

** this represents the participant portion that selected 'Yes'(n =34) to receiving a diagnosis out of the 65*

*** This is based on a multiple-choice question selection thus the percentages are based on the n=65 with the percentage for each professional reflecting the amount out of 65 who selected that professional*

Sex-based Diagnostic Patterns

Table 2 provides sex-based comparisons of diagnosis status, age at diagnosis, and timing of first concerns. Males were diagnosed more frequently *(n-41; 63%)* than females *(n=23; 35%)*, though both groups experienced similar delays (>12 months = 39% across sexes). The average age of first concern (6-12 months) was similar between groups. Caregivers of female children more often described encountering barriers early *(n=14; 61%),* whereas caregivers of male cases reported barriers across broader range of ages *(n=27; 66%)*.

Male children were more likely have already been diagnosed *(n=23;35.38%)* while female children were more commonly awaiting a formal diagnosis *(n=10;15.38%)* (Table 2).

Table 2

Survey participant child diagnosis status, age diagnosed, and time since concerns, organised by gender

Variable	**Female (n=23)**	**Male (n=41)**	**Other/prefer not to say**
Received autism diagnosis	10 (15.38%)	23 (35.38%)	0 (0%)
Age of child diagnosed*			
2 years	3 (4.62%)	5 (7.69%)	0 (0%)
3 years	2 (3.08%)	5 (7.69%)	0 (0%)
4 years	1 (1.54%)	4 (6.15%)	0 (0%)
5 years	1 (1.54%)	3 (4.62%)	0 (0%)
6 years	2 (3.08%)	6 (9.23%	0 (0%)
Time since concerns first noticed> 12 months*	9 (39%)	16 (39%)	1 (1.54%)
Age when concerns first noticed*	Mostly 6-12 months (26%) and 1-2 years (26%)	Mostly 6-12 months (27%) and 1-2 years (27%)	1-2 years (1.54%)
Did you experience barriers?			
2 years	3 (4.62%)	2 (4.62%)	0 (0%)
3 years	2 (3.08%)	5 (7.69%)	0 (0%)
4 years	0 (0%)	4 (6.15%)	0 (0%)
5 years	0 (0%)	1 (1.54%)	0 (0%)

6 years	2 (3.08%)	6 (9.23%)	1 (1.54%)

**NOTE: percentages are calculated within each gender category; bracketed values show the proportion of the overall sample (n=65). Data sourced by participant survey pivot-table output. Percent of all diagnosed respondents (n=35)*

** 3 stated they did not experience barriers at 2 years*

Barriers to Diagnosis

Outlined in Table 3, almost nine in ten participants (87.7%) reported at least one barrier to diagnosis. The most frequent were high out-of-pocket costs (*n=45;73.9%),* long wait times *(n=44;67.7%),* and limited navigation support *(n=33;50.8%).* Nearly half *(n=31;47.7%)* were unsure how to begin the diagnostic process, and 28 (43%) cited limited specialist availability. Rural and regional accessible difficulties *(n=13;20%)* were more common than cultural or language barriers *(n=1;1.5%).* Over half of the participants felt involved in decision-making *(n=37; 56.9%),* while 18.5% *(n=12)* felt uninvolved and 14.6% *(n=16)* were neutral. Perceptions of support were mixed, 46.2% *(n=30*) felt supported, 43.1% *(n=28)* felt unsupported, and 10.8% *(n=7)* were neutral.

Table 3

Survey participant barriers experienced during diagnostic process

Barrier	**Category**	**N (%)**
Did you experience barriers*	Yes	57 (87.69%)
	No	8 (12.31%)
The barriers: Long wait times*		44 (67.69%)
High out-of-pocket costs*		48 (73.85%)
Knowing where to start*		31 (47.69%)

Limited availability of specialists*		28 (43.08%)
Lack of support navigating services*		33 (50.77%)
Rural or regional access*		13 (20.00%)
Language or cultural*		1 (1.54%)
Other*		7 (10.77%)
"I felt supported throughout the diagnostic process"	Strongly disagree	5 (7.69%)
	Neither agree or nor disagree	7 (10.77%)
	Somewhat agree	19 (29.23%)
	Somewhat disagree	14 (21.54%)
	Strongly agree	11 (16.92%)
	Strongly disagree	14 (21.54%)
"I was actively involved in decision-making throughout the process"	Neither agree nor disagree	16 (24.62%)
	Somewhat agree	20 (30.77%)
	Somewhat disagree	7 (10.77%)
	Strongly agree	17 (26.15%)

** this data is based on the percentage out of the participants (65) who selected this choice*

Awareness of Autism Related Initiatives and Bodies

Awareness of autism-related initiatives was limited (Table 4). Only 36.9% *(n=34)* were aware of the Office for Autism, 38.5% *(n=25)* the Autism Inclusion Teacher Initiative, and 27.7% *(n=18)* k the Inklings Early Identification Pilot. In contrast, awareness of Autism SA (*n=62;95%)* and NDIS (*n=63*;*97%)* was almost universal.

Table 4

Survey participant awareness of initiatives and autism bodies nationally and state based (Q14-19)

Initiative or body	**Category**	**N (%)**

Office for Autism	Yes	24 (36.92%)
	No	41 (63.08%)
Autism Inclusion Teacher Initiative	Yes	25 (38.46%)
	No	40 (61.54%)
Inklings Early Identification Pilot Program	Yes	18 (27.69%)
	No	47 (72.31%)
Autism SA	Yes	62 (95.38%)
	No	3 (4.622%)
National Disability Insurance Scheme (NDIS)	Yes	63 (96.92%)
	No	2 (3.08%)
Have you accessed any of the above?	Yes	48 (73.85%)
	No	17 (26.15%)

Confidence in Collaborative Diagnostic Models

Participants strongly supported collaborative diagnostic models (Table 5). Confidence in collaborative was highest for psychologists (*n=52;80%)*, occupational therapists (n=49;*75%),* and speech pathologists (*n=48;74%),* while lower for general practitioners (*n=36;55%)* and nurses (*n=20;31%)*. Overall, 80% (*n=52)* endorsed interdisciplinary approached integrating medical and allied health expertise.

Table 5

Collaborative diagnostic model of professional's survey participants would be comfortable having involved in diagnosing their child (Q22)

Collaborative body	**Category**	**N(%)**
General practitioners (GP's)	Yes	36 (55.38%)
	No	29 (44.62%)
Nurses	Yes	20 (30.77%)
	No	45 (69.23%)

Speech pathologist	Yes	48 (73.85%)
	No	17 (26.15%)
Occupational therapist	Yes	49 (75.38%)
	No	16 (24.62%)
Psychologist	Yes	52 (80.00%)
	No	13 (20.00%)
Other	Yes	4 (6.15%)
	No	61 (93.85%)

** the 'No' portion of each multiple-choice option represents the participants who did not select that option out of the 65*

Summary of Quantitative Findings

In summary, this educated, predominately female, part-time employed, cohort reported substantial financial and systemic barriers to diagnosis, low awareness of new South Australian reforms, and strong support for allied-health-led collaborative assessment.

Qualitative Interview data

Six (*N=6)* semi-structured interviews (P1-P 6) provided deeper insight into caregiver experiences. Reflexive thematic analysis generated four overarching themes and nineteen subthemes, reflecting emotional, structural, and contextual factors shaping the diagnostic journey for South Australian families (Figure 1).

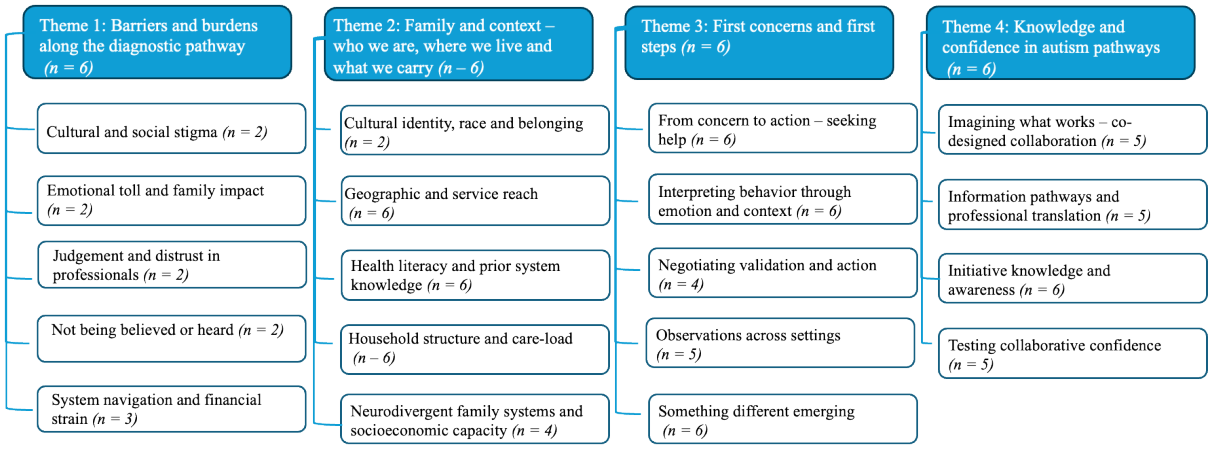

Figure 1: visual representation of themes and subthemes represented by interview participants (*N = 6)*

Theme 1: Barriers and Burdens along the diagnostic pathway (5 subthemes)

This theme comprised five subthemes, reflecting caregiver's descriptions of diagnostic processes as exhausting, fragmented, and emotionally taxing. Participants (*n=6)* consistently linked long waits, repeated assessments, and inconsistent advice to escalating strain.

Subtheme 1.1: Cultural and Social Stigma

Participants reported stigma within extended family or community networks that compounded emotional distress. One participant explained, *"My partner's family stopped speaking to us entirely."* (P1), highlighting how stigma extended beyond clinical encounters.

Subtheme 1.2: Emotional Toll and Family Impact

Participants described depletion and stress across the household. As one participant stated, *"I still struggle with my son even though I know the system...is still such a problem."* (P2), illustrating ongoing emotional burden.

Subtheme 1.3: Judgement and Distrust in Professionals

Dismissive or judgemental responses from clinicians eroded trust. One participant recalled, *"[The paediatrician] couldn't figure out how she could be so intelligent but also struggle...it was just the judgement from there that trust…was really gone."* (P1).

Subtheme 1.4: Not being Believed or Heard

"Watch-and-wait" advice was a reoccurring pattern across all interviews. For example, *"He [psychologist] said 'just give it more time...watch and wait."* (P1). Participants described persistent dismissal despite repeated concerns.

Subtheme 1.5: System Navigation and Financial Strain

Participants reported high financial costs, rejected referrals, and difficulty accessing providers. As one participant summarised, *"We're currently…. pursuing the autism diagnosis, but in navigating the wait list, we really do not have much…for pursuing private options."* (P4).

Theme 2: Family and context – who we are, where we live and what we carry (5 subthemes)

This theme comprised five subthemes, illustrating how diagnosis experiences were shaped by cultural identity, socioeconomic capacity, household structure, and geographic location.

Subtheme 2.1: Cultural identity, race and belonging

Cultural norms influenced by trust and responses to diagnosis. One participant described, *"My black husband has such a distrust of the medical system...his family believe an autism diagnosis means something evil."* (P1).

Subtheme 2.2: Geographic and service reach

Participants in regional areas described markedly reduced access to autism services,*"...being out in the country versus being in the city…we just have such limited resources like we don't have anything really."* (P2).

Subtheme 2.3: Health literacy and prior system knowledge

Even highly educated participants found the system difficult to navigate, with one noting, "…*if it's hard enough for me to navigate this, what about somebody with less education?..."* - (P3),

Subtheme 2.4: Household structure and care-load

Participants described balancing employment, caregiving, and specialist appointments,*" I can't work as much as I need to…so like no penalty rates. And I'm constantly at my daughter's school…(*P1).

Subtheme 2.5: Neurodivergent family systems and socioeconomic capacity

Multiple participants had more than one neurodivergent family member, compounding strain. One participant explained, *"three children…all neurodivergent."* (P2).

Theme 3: First concerns and first steps (5 subthemes)

This theme comprised five subthemes, capturing caregivers' early recognition of developmental differences and their efforts to seek validation and assessment.

Subtheme 3.1: From concerns to action – seeking help

Participants often recognised differences early. As one participant described, "*my son's been on NDIS since 17 months…we just decided that before school.."* (P6).

Subtheme 3.2: Interpreting behaviour through emotion and context

Participants discussed challenges interpreting behaviours, particularly among girls, *"I have high-masking, clever, well-presenting daughters…that is hard."* (P5).

Subtheme 3.3: Negotiating validation and action

Dismissal by professional prompted self-advocacy. One participant noted, *"Initially…I saw our local paediatrician, she said no way…so I go another referral."* (P2).

Subtheme 3.4: Observations across settings

Educators played a prominent role in validating concerns, *"Daycare were very concerned...they were key in bringing those concerns forward."* (P5).

Subtheme 3.5: Something different emerging

Participants frequently self-initiated allied-health pathways, *" We actually went to an OT at a children's centre initially."* (P1).

Theme 4: Knowledge and confidence in autism pathways (4 subthemes)

This theme comprised four subthemes, reflecting participant awareness of autism initiatives and preferences for collaborative diagnostic models.

Subtheme 4.1: Imaging what works – co-designed collaboration

Participants envisioned blended models integrating accessibility and specialist oversight, *" I like the hospital model…access to a doctor anytime…something like that would be great."* (P3).

Subtheme 4.2: Information pathways and professional translation

Participants emphasised the need for clearer information-sharing, *"The paediatrician could go through professional...observations instead of repeating them."* (P4),

Subtheme 4.3 – Initiative knowledge and awareness

Awareness of state-level initiatives was limited. One participant stated, *"I had not heard of that programme…"* (P3), and another, *"The Office for Autism…not sure about that one, no."* (P2).

Subtheme 4.4: Testing collaborative confidence

Participants endorsed an allied-health-led model with oversight for complex cases, *"there would need to be some sort of backup level of more experienced."* (P3). Expressing desired unified pathways, *"be great if there was like a centralised…department of you know.."* (P6).

Interview narratives directly mirrored the survey's dominant barriers (high out-of-pocket costs 73.9%, long waits 67.7%, limited navigation support 50.8%) and low awareness of state-specific initiatives (Office for Autism 36.9%, Inklings 27.7%, Autism Inclusion

Teacher Initiative 38.5%), while reaffirming families' early engagement with allied health (speech 61.5%, psychology 49.3%, occupational therapy (38.5%) ahead of primary care.

Discussion

This discussion addresses the study's four aims by integrating quantitative and qualitative findings to examine systemic barriers, participants navigation experiences, awareness of autism initiatives, and confidence in collaborative diagnostic models. Overall, caregivers described consistent patterns of long waits, high out-of-pocket costs, and unclear referral pathways, with many relying on self-navigation due to limited coordination and inconsistent communication. Awareness of South Australia's reforms was lower than anticipated for an educated cohort, while confidence in allied-health involvement in diagnosis was strong when supported by clear governance. These findings align with Evans et al. (2025), who observed fragmented pathways and parental case-management burden, extending this understanding into early-childhood diagnostic window examined in this study. Findings are discussed by aim.

Aim 1: Examine systemic and structural barriers influencing diagnostic delay

Consistent with Hypotheses 1, families reported prolonged wait times, financial strain, and unclear or inconsistent referral pathways, with these pressures particularly salient for rural households. Participants described interacting financial, temporal, and coordination barriers, reinforcing national literature on lengthy waits and escalating costs (Ward et al., 2016; Boulton et al., 2024). Qualitative data illustrated how these pressures accumulated. For example, one caregiver described professionals attributing concerns to parental factors rather than clinical statements, stating a psychiatrist *"looked at the records and said it was a 'parent issue'"* (P2). This reflected the subtheme of professional minimisation, aligning with

critiques of the "watch-and-wait" culture in early childhood assessment (Smith-Young et al., 2020; Smith-Young et al., 2022).

Participants also described emotional and relational impacts, including stigma and interpersonal strain. One participant noted that extended family *"stopped speaking to us."* (P1), demonstrating how stigma and misunderstanding compounded systemic delays. These findings illustrate the cultural and social strain subtheme, extending evidence that inequity is shaped not only by service structures but also family and community dynamics.

Geographic barriers were salient for regional participants, who reported very limited-service reach. These findings are consistent with the Autism CRC's (2023) identification of geographic maldistribution and extend it by demonstrating fragmentation even within the critical 2-6 year diagnostic window. Integrated findings suggest that national reforms, such as the National Autism Strategy (2025), have not yet translated into consistent diagnostic pathways, underscoring the need for clarity regarding diagnostic authority, structured navigation roles, and stronger interprofessional communication.

Aim 2: Capture caregivers' experiences of navigating the diagnostic process within family and contextual realities

Even highly educated and motivated caregivers described persistent confusion and inconsistent professional guidance, illustrating that systemic opacity, not parental literacy, was the central barrier. As one participant reflected, *"if it's hard enough for me to navigate this, what about somebody with less education managing this."* (P3). This aligns with the health literacy and prior system knowledge subtheme, emphasising that self-directed research often substituted for professional support.

Financial strain and care-load were significant across families, particularly those with multiple neurodivergent children. Participants described adjusting work hours or stepping back from employment to accommodate repeated appointments and long waits, consistent with household structure and socioeconomic capacity challenges. Geographic inequities reiterated stressors for regional families, reflecting geographic and service reach subtheme.

Sex-based patterns highlighted emerging improvements identifying autistic girls, with caregivers describing difficulties related to masking and less overt presentation. One participant described their daughter as *"very social, but they didn't see what I see at home."* (P2), illustrating the ongoing challenges of recognising less typical presentations despite growing professional awareness (Hull et al., 2020).

Aim 3: Assess awareness and engagement with national and South Australian autism initiatives and referral processes

Supporting Hypotheses 2, awareness of South Australia's newer autism reforms was low, with higher awareness of national larger initiatives, consistent with expectations given their early implementation stage. Awareness of long-established bodies such as Autism SA and the NDIS was high, however, awareness of newer South Australian reforms, the Office for Autism, Autism Inclusion Teacher Initiative, and the Inklings Early Identification Pilot, remained low despite participants' high educational attainment. This aligned with the initiative knowledge and awareness subtheme and supports previous findings that local reform messaging often lacks visibility (Rasheed, 2023).

Participants frequently expressed uncertainty regarding the purpose or processes of these initiatives. One participant stated they had *"heard of the Office for Autism but didn't*

know what it was for." (P4), illustrating the disconnect between policy intent and public understanding. Despite early detection of developmental differences, many experienced delays of more than 12 months, demonstrating that vigilance alone does not result in early action. Consistent with Bent et al. (2015) and Gibbs et al. (2019), these findings highlight the persistent gap between early parental identification and systemic validation.

Aim 4: Guage caregiver confidence in collaborative, multidisciplinary diagnostic models and awareness of autism initiatives

In line with Hypotheses 3, families expressed strong support for multidisciplinary and allied-health-inclusive diagnostic models, provided governance structures were clear. Participants showed strong confidence in allied-health professionals, psychologists, occupational therapists, and speech pathologists, reflecting the testing collaborative confidence subtheme. Confidence in general practitioners and nurses was lower, suggesting uncertainty about training, scope and diagnostic authority. Participants emphasised the need for structured oversight for complex cases, describing the importance of having *"more experience professionals available if needed."* (P3).

Participants often bypassed GP gatekeeping, initiating assessment pathways directly through allied-health services, demonstrating a de-facto multidisciplinary model formed out of necessity rather than coordinated design. This pattern is consistent with national findings highlighting growing caregiver confidence in allied-health-inclusive diagnostic pathways (Whitehouse et al., 2021). The imagining what works subtheme further illustrated parents' preference for co-designed models combing accessibility with clear governance.

Integrated findings indicate that while families strongly endorse collaborative models, persistent ambiguity regarding diagnostic authority and referral pathways limits the capacity

of reforms to take effect. Structured governance and clear escalation pathways are needed to translate multidisciplinary principles into practice.

Integrated interpretation

Taken together, these findings depict early autism diagnosis in South Australia as a function of structural arrangements rather than individual caregiver capacity. Long waits, out-of-pocket costs, and opaque referral processes align with broader accounts of system-level barriers to developmental assessment, while low awareness of state reforms and reliance on allied-health-led pathways highlight gaps between policy intent and everyday practice (Autism CRC, 2018; Bent et al., 2015; Evans et al., 2025). Within a social determinant's framework, governance clarity, funding structures, and information pathways become levers for change, suggesting that improvements in diagnostic equity will depend on how national and state strategies are operationalised across services rather than on further exhortations for parents to advocate more effectively (WHO, 2025; DSS, 2025). Addressing these structural gaps through co-designed, allied-health-inclusive pathways with defined accountability and escalation processes will be essential to enforcing the goals of national and state autism reforms and reducing diagnostic delays within the early-childhood period.

Implications

Policy and systems

Clear, state-endorsed diagnostic governance is needed to clarify professional authority, referral responsibilities, and escalation pathways across health, education, and disability sectors. Embedding structured navigation roles and improving the visibility of state reforms, such as the Office for Autism, Autism inclusion Teachers, and the Inklings Pilot, would reduce duplication, strengthen accountability, and support equitable access

Clinical and critical practice implication

Clinical practice reforms should focus on establishing multidisciplinary diagnostic hubs with clear role delineation, supported by targeted training in referral processes, early identification, and interprofessional communication. These hubs would enable allied-health clinicians to undertake structured assessments with medical oversight for complex presentations, aligning with the national recommendations for coordinated, collaborative diagnostic pathways.

Future research

As the first mixed-methods investigation within South Australia reform era, this study establishes an empirical baseline against which future policy and practice changes can be evaluated. Longitudinal research should examine whether emerging governance reforms improve diagnostic timelines, clarify professional role boundaries, and strengthen navigation pathways for families. Future work should also assess the effectiveness of allied-health-inclusive diagnostic hubs, including escalation processes and cross-sector collaboration, to determine whether these models reduce fragmented and enhance equity. Further research is required to understand diagnostic experiences among culturally and linguistically diverse families, regional households, and low-SES communities, who were under-represented in this sample. Evaluating how national initiatives such as the National Autism Strategy align with lived diagnostic experiences across jurisdictions will be critical as reforms progress. Findings reveal that although Australia endorses multidisciplinary assessment as best practice (Autism CRC, 2018; Vivanti & Whitehouse, 2021), implementation remains partial and inconsistent, relying on individual clinicians rather than cohesive system design. For example, mixed-methods implementation studies or pragmatic trials comparing different service models, such as hospital-based multidisciplinary clinics, community-based allied-health-led hubs, and

hybrid arrangements, could clarify which configurations most effectively reduce delays, support caregiver trust, and deliver guideline-concordant assessment in real-world contexts (Frakking et al., 2022; Autism CRC, 2023).

Strengths and limitations

A central strength of this study lies in its convergent mixed-methods design, integrating the breadth of quantitative survey data with the depth of qualitative interviews (Creswell & Plano Clark, 2018). This approach enabled a rich, policy-embedded understanding of caregiver experiences during a period of active reform in South Australia. It is also the first state-based investigation to explore autism diagnostic equity within its specific reform environment, providing contemporary, contextually grounded evidence that complements national research. This study further offers unique insight by quantitatively mapping caregiver confidence across diagnostic disciplines, highlighting an emerging allied-health-led confidence model consistent with calls for more transparent diagnostic practice (Ward et al., 2016; Taylor et al., 2016). The researcher's dual perspective as a clinician-academic and caregiver enhanced interpretive sensitivity and contextual depth, strengthened through ongoing supervision and reflexive practice. By explicitly situating caregiver narratives within the context of current national and state reforms, the study also offers policy-relevant evidence that can inform the implementation and evaluation of the National Autism Strategy and the South Australian Autism Strategy in practice (DSS, 2025).

However, several limitations must be acknowledged. The modest sample size limits generalisability, and the predominantly tertiary-educated, metropolitan cohort likely represents a best-case scenario, suggesting that inequities may be even more pronounced

among regional, culturally diverse, or lower-SES families. The South Australian-specific context also limits transferability as diagnostic governance, service availability, and reform timelines differ across jurisdictions.

Recruitment via advocacy networks may have overrepresented engaged or system-aware caregivers, and the cross-sectional design restricts the ability to assess changes over time or evaluate reform impact longitudinally. Although reflexive strategies were employed, the researcher's positionality may still have influenced interpretation. Finally, culturally and linguistically diverse communities and non-English-speaking families were underrepresented, indicating a priority area for future research.

Conclusion

This mixed-methods study offers preliminary insight into how systemic fragmentation, financial strain, and unclear diagnostic authority may contribute to delays in early autism diagnosis in South Australia. Despite high caregiver literacy and engagement, access remained inequitable due to governance ambiguity and inconsistent referral pathways. Families demonstrated strong confidence in allied-health-led collaboration when supported by transparent structures and adequate oversight, highlighting the potential value of coordinated, interdisciplinary approaches.

Achieving equitable, timely diagnosis will likely require gradual, evidence-informed improvements in governance clarity, strengthened navigation roles, and consideration of subsidised early assessment pathways across health and education systems. While findings are shaped by a modest, predominately metropolitan sample, they offer an early identification of system features that warrant further investigation as South Australia progresses through a period of reform. In meeting its four aims, the study showed that barriers, caregiver

experiences, initiative awareness and confidence in collaborative models are not separate challenges but interconnected drivers of diagnostic delay. This integrated evidence underscores the need for unified, transparency pathways that empower families while strengthening the coordination and accountability of South Australia's evolving reform environment. Overall, the findings supported the study's three hypotheses, demonstrating that systemic barriers disproportionately affected families, awareness of new South Australian reforms remained low, and multidisciplinary allied-health models were strongly endorsed when supported by clear governance.

Rather than making definitive claims, this study underscores emerging areas where policy, clinical practice, and family experience could be more closely aligned. South Australia's reform environment presents an opportunity to trial, refine and evaluate multidisciplinary models that may, with further evidence, support national efforts under the National Autism Strategy. Future research with larger, more diverse samples will be essential to build on these exploratory findings and more confidently inform statewide and national diagnostic pathways.

Supplementary data

The full survey instrument and interview guide are provided as supplementary files:

Appendix A – Survey Instrument (Qualtrics PDF)

Appendix B – Interview Guide (PDF)

References

Agency for Clinical Innovation (2024). Children (0-5 years) presenting with developmental concerns: Clinical practice guide. *NSW Agency for Clinical Innovation*. https://aci.health.nsw.gov.au.

American Psychiatric Association. (2022). Diagnostic and statistical manual of mental disorders (5th ed., text rev.). https://doi.org/10.1176/appi.books.9780890425787.

AMAZE. (2019). Submission 201 – Mental Health: Productivity Commission's inquiry into the role of improving mental health to support economic participation and enhancing productivity and economic growth (Submission No. 201). https://assets.pc.gov.au/__data/assets/pdf_file/0017/240452/sub201-mental-health.pdf.

Australian Institute of Health and Welfare (AIHW). (2024). People with disability in Australia 2024 (Cat.np. DIS 72). Australian Government. https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia-2024.

Autism CRC. (2018). *National guideline for the assessment and diagnosis of autism spectrum disorders in Australia*. https://www.autismcrc.com.au/knowledgecentre/resource/national-guideline

Autism CRC. (2023). *National guideline for the assessment and diagnosis of autism in Australia: 2023 update*. https://www.autismcrc.com.au/best-practice/assessment-and-diagnosis/guideline

Babalola, T., Sanguedolce, G., & Dipper, L. (2024). Barriers and facilitators of healthcare access

for autistic children in the UK: A systematic review. *Review Journal of Autism and Developmental Disorders.* https://doi.org/10.1007/s40489-023-00420-3.

Bent, C. A., Dissanayake, C., & Barbaro, J. (2015). Mapping the diagnosis of autism spectrum disorders in children aged under seven years in Australia. *Medical Journal of Australia, 202*(6), 317–320. https://doi.org/10.5694/mja14.00328

Berger, R. (2013). Now I see it, now I don't: Researcher's osition and reflexivity in qualitative research. *Qualitative Research*, *15*(2), 219-234. https://doi.org/10.1177/1468794112468475.

Boulton, K. A., Hodge, A., Levu, K., Ong, N., Silove, N., & Guastella, A. (2024). Access and barriers to supports for children attending public developmental assessment services. *Autism Research, 17*(3), 555–567. https://doi.org/10.1002/aur.3064

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101. https://doi.org/10.1191/1478088706qp063oa.

Creswell, J. W., & Plano Clark, V. L. (2017). Designing and conducting mixed methods research (3rd ed.). *SAGE Publications.*

Department of Health and Aged Care. (2025). National roadmap to improve the health and mental health of autistic people 2025-2035. https://www.health.gov.au/sites/default/files/2025-02/national-roadmap-to-improve-the-health-and-mental-health-of-autistic-people-2025-2035.pdf.

Department of Social Services (DSS). (2025). National Autism Strategy 2025–2031. *Australian Government.* https://www.dss.gov.au.

Eapen V. (2016). Early identification of *autism* spectrum disorder: Do we need a paradigm shift?. *Australian and New Zealand Journal of Psychiatry*, *50*(8), 718–720. https://doi.org/10.1177/0004867416652733.

Eapen V., Winata, T., Gilbert, M., et al. (2022). Parental experience of an early developmental surveillance programme for autism within Australian general practice: A qualitative study. *BMJ Open*, *12,* e064375. https://doi.org/10.1136/bmjopen-2022-064375.

Evans, S., Pringle, H., Sandner, Z., Hayley, A., (2025). Exploring parents' experiences of interprofessional collaboration among health professionals in the assessment and support of autistic children. *Journal of Interprofessional Care.* https://doi.org/10.1080/13561820.2025.2462131.

Fetters, M.D., Curry, L.A., & Creswell, J.W. (2013). Achieving integration in mixed methods designs- Principles and practices. *Health Services Research, 48*(6 Pt 2), 2134-2156. https://doi.org/10.1111/1475-6773.12117.

Frakking, T.T., Waugh, J., Carty, C., Burmeister, A., Marozza, A., Hobbins, S., Kilah, M., David, M., Kane, L., McCormick, S., & Carter, H.E. (2022). The effect of different service models on quality of care in the assessment of autism spectrum disorder in children: Study protocol for a multi-centre randomised controlled trial. *BMC Pediatrics, 22*, 173. https://doi.org/10.1186/s12887-022-03244-y.

Gibbs, V., Aldrigde, F., Sburlati, E., Chandler, F., Smith, K. (2019). Missed opportunities: An investigation of pathways to autism diagnosis in Australia. *Research in Autism Spectrum Disorders, 57*, 55-62. *https://doi.org/10.1016/j.rasd.2018.10.007.*

Gibbs, V., Cai, R. Y., Aldridge, F., & Wong, M. (2021). Autism assessment via telehealth during the Covid 19 pandemic: Experiences and Perspectives of autistic adults, parents/carers and clinicians. *Research in Autism Spectrum Disorders, 88,* 101859. https://doi.org/10.1016/j.rasd.2021.101859.

Government of South Australia. (2024). *SA Autism Strategy 2024-2029*. https://inclusive.sa.gov.au/__data/assets/pdf_file/0004/168745/Autism-Strategy-2024-2029.pdf.

Hussain, A., et al. (2023). Sociocultural factors associated with detection of autism among CALD communities in Australia. *BMC Pediatrics*, *23*, 415. https://doi.org/10.1186/s12887-023-04236-2.

Hull, L., Lai, M.- C., Baron-Cohen, S., Allison, C., Smith, P., Petrides, K. V., & Mandy, W. (2020). Gender differences in self-reported camouflaging in autistic and non-autistic adults. *Autism*: *The International Journal of Research and Practice*, *24*(2), 352-363. https://doi.org/10.1177/1362361319864804.

Lo, B.H., Klopper, F., Barnes, E., and Williams, K. (2018). Autism spectrum disorder. *Journal of Paediatrics and Child Health*, *54*(2), 212-213. https://doi.org/10.1111/jpc.13841.

National Health and Medical Research Council (NHMRC). (2025). *Procedures and requirements for meeting NHMRC standards for clinical practice guidelines.* Australian Government.

Nowell, L.S., Norris, J.M., Moules, N.J., & White, D.E. (2017). Thematic analysis: Striving to meet the trustworthiness criteria. *International Journal of Qualitative Methods, 16(*1). https://doi.org/10.1177/1609406917733847.

Rasheed, Z. (2023). Autism in Australia: Understanding, challenges, and

support. *International Journal of Health Sciences*, *17*(5), 1–4. https://pmc.ncbi.nlm.nih.gov/articles/PMC10484064/pdf/IJHS-17-1.pdf.

Smethurst, G., Williams, G., & Lannin, N.A. (2021). Controlled choice, not choice and control: Families' reflections after one year using the National Disability Insurance Scheme. *Australian Occupational Therapy Journal, 68*(3), 205-216. https://doi.org/10.1111/1440-1630.12715.

Smith-Young, J., Chafe, R., & Audas, R. (2020*).* "Managing the wait": Parents' experiences in accessing diagnostic and treatment services for children and adolescents diagnosed with autism spectrum disorder. *Health Services Insights*, *13.* 1-10. https://doi.org/10.1177/1178632920902141.

Smith-Young, J., Chafe, R., Audas, R., & Gustafson, D. L. (2022). "I know how to advocate": Parents' experiences in advocating for children diagnosed with autism. *Health Services Insights, 15*, 1–10. https://doi.org/10.1177/11786329221078803.

Taylor, L. J., Eapen, V., Maybery, M. T., & Whitehouse, A.J.O. (2016). Diagnostic evaluation for autism spectrum disorder: A survey of health professionals in Australia. *BMJ Open, 6(*9), e012517. https://doi.org/10.1136/bmjopen-2016-012517.

Vivanti, G., & Messinger, D.S. (2021). Theories of autism and autism treatment from the DSM-III through the present and beyond: Impact on research and practice. *Journal of Autism and Developmental Disorders, 51,*4309-4320. https://doi.org/10.1007/s10803-021-04887-z.

Ward, S.L., Sullivan, K.A., & Gilmore, L. (2016). Practitioner perceptions of the

assessment and diagnosis of autism in Australia. *Australian Psychologist, 51*(4), 272-279. https://doi.org/10.1111/ap.12211.

Whitehouse, A. J. O., Evans, K., Eapen, V., & Wray, J. (2018). A national guideline for the assessment and diagnosis of autism spectrum disorders in Australia. *Autism CRC.* https://www.autismcrc.com.au/knowledge-centre/resource/national-guideline.

World Health Organization. (2025). *Social determinants of health*. https://www.who.int/health-topics/social-determinants-of-health.

Zwaigenbaum, L., Baunman, M.L., Stone, W.L., Yirmiya, N., Estes, A., Hansen, R.L., …Wetherby, A.M. (2015). Early identification of autism spectrum disorder: Recommendations for practice and research. *Pediatrics, 136* (Suppl.1), S10-S40. https://doi.org/10.1542/peds.2014-3667C.