Autism Spectrum Disorder Diagnosis in Australia

ARE WE MEETING BEST PRACTICE STANDARDS?

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The Cooperative Research Centre for Living with Autism (Autism CRC)

The Cooperative Research Centre for Living with Autism (Autism CRC) is the world's first national, cooperative research effort focused on autism. Taking a whole of life approach to autism focusing on diagnosis, education and adult life, Autism CRC researchers are working with end-users to provide evidence-based outcomes which can be translated into practical solutions for governments, service providers, education and health professionals, families and people with autism.

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Executive Summary

There is currently no consistent Australian standard for diagnosis of Autism Spectrum Disorder (ASD). As a consequence, discrepant diagnostic practices across states and between clinicians are likely. In 2015, we conducted a survey of 173 health professionals whose clinical practice includes participating in diagnostic assessments for ASD. Participants from a range of disciplines completed an online questionnaire which contained questions about their diagnostic setting, diagnostic practices and diagnostic outcomes. The results confirmed that there is a lack of consistency in diagnostic practices across Australia and that some professionals may not be practicing in a way that is consistent with international best practice guidelines for ASD diagnosis.

DIAGNOSTIC PROCESSES

- Most clinicians conduct at least two assessment sessions before making an ASD diagnosis. The length of assessment sessions are significantly longer in the public sector compared to the private sector.

- There are more multidisciplinary assessment teams in the public sector than in the private sector. While multidisciplinary teams usually conduct assessments together, sole practitioners rarely collaborate with other professionals to make diagnostic decisions.

- Most assessments occur in the clinic setting, with health professionals seldom observing an individual in other settings, such as at school or home.

DIAGNOSTIC PRACTICES

- Most participating paediatricians reported that they include a hearing test and other medical investigations (genetic screen, Fragile X test, neurological and physical examinations) in diagnostic assessments for ASD.

- One third of the respondents reported that they did not include measures of development, cognition and language in ASD assessments.

- Approximately half of the respondents reported that they include an Autism Diagnostic Observation Schedule (ADOS) as part of their ASD assessments work up. Only 30% of the participating clinicians indicated that they include both the ADOS and the Autism Diagnostic Interview-Revised (ADI-R) in diagnostic assessments for ASD.

DIAGNOSTIC OUTCOMES

- In 2014-2015, 58% of the assessments completed by participating health professionals resulted in an ASD diagnosis.

- There was a higher frequency of ASD diagnoses being provided in the private relative to the public sector, and for sole practitioners compared to

multidisciplinary teams. It is possible that this finding reflects different types of clinical presentations across settings.

- Only 2.4% of assessments during this period resulted in diagnoses of Social (Pragmatic) Communication Disorder.

- A small number of health professionals reported having diagnosed ASD when an individual does not meet criteria for the disorder, usually to ensure that the individual can access intervention or support services.

THE LOGISTICS OF ASD DIAGNOSIS IN AUSTRALIA

- There was variability in wait list times across the nation, with longer waiting periods for public services relative to private services.

- There was considerable variability in the cost of ASD assessments. In the public sector, the cost to families was $0 and in the private sector, the cost ranged from $200 to $2750.

DIAGNOSIS IN REGIONAL, RURAL AND REMOTE AUSTRALIA

- Few clinicians provided diagnostic assessments for ASD in regional, rural and remote areas of Australia.

- The wait for a diagnostic assessment in these regions was significantly longer than the wait list period for families in major cities.

CONCLUSION AND RECOMMENDATIONS

- There is considerable variability in diagnostic practices for ASD across Australia.

- Diagnostic assessments for ASD in Australia may not always be consistent with international best practice guidelines.

- Adopting a minimum national standard for ASD diagnosis across Australia would improve diagnostic practices, ensure consistency across the country, and that future diagnostic assessments are in keeping with best practice guidelines.

Autism Spectrum Diagnosis in Australia

ARE WE MEETING BEST PRACTICE STANDARDS?

Background

In the absence of biomarkers, diagnosis of Autism Spectrum Disorder (ASD) is based on the behavioural presentation of an individual. The 'gold standard' in ASD diagnosis is a best estimate clinical diagnosis which is determined in accordance with current diagnostic classification systems and following rigorous assessment practices. There is general consensus that rigorous diagnostic assessments consist of a physical examination, hearing test, child observation and parent interview which includes a full developmental history (NICE, 2011). 'Best-practice' ASD assessments are more comprehensive, and also comprise standardized developmental or cognitive testing, language assessment and information from more than one setting, ideally from a source other than the parent or carer who has been interviewed (Anagnostou et al., 2014; Baird et al., 2003; Filipek et al., 2000; NICE, 2011; Ozonoff et al., 2005). The assessment results are used to inform diagnostic decision-making, which is based on current diagnostic classification systems including the Diagnostic and Statistical Manual, currently in its 5th iteration (DSM-5; American Psychiatric Association, 2013) or the International Classification of Diseases-10 (ICD 10; World Health Organisation, 1992). Rigorous assessments enhance the accuracy of diagnoses and provide information about an individual's strengths and difficulties which is important for intervention planning.

Despite the internationally recognized best practice guidelines for ASD diagnosis (e.g. NICE, 2011), and position statements from Australian professional bodies (Australian Advisory Board on Autism Spectrum Disorder, 2011; Royal Australasian College of Physicians, 2008; Western Australian Autism Diagnostician's Forum; see also Glasson et al., 2008) Australia does not have a national standard for ASD diagnosis. In addition, health services are governed on a state or territory basis, rather than a national level. While in some jurisdictions, eligibility for publicly-funded intervention for children with ASD requires a diagnosis made by a multidisciplinary team comprising a medical professional, psychologist and speech pathologist, other states have less stringent criteria, requiring only a paediatrician or psychiatrist. Furthermore, eligibility for funding from the Helping Children with Autism package is determined following a conclusive ASD diagnosis which can be provided by a single paediatrician or psychiatrist (Australian Government, 2015). However, eligibility for funding for early intervention may change under the impending National Disability Insurance Scheme (NDIS), which will allow for children with global developmental delay without an ASD diagnosis to access early intervention services.

The landscape of ASD diagnosis in Australia is further complicated by the geographic dispersion of the population. Families are spread across metropolitan, regional, rural and remote settings, each of which presents unique challenges to clinical practice. Families in rural areas may have difficulty gaining access to GPs (Leveratt, 2007) and there is a lower number of specialist medical professionals practicing in more remote areas of Australia (AIHW, 2008), creating barriers to accessing timely clinical care. This may contribute to the variability in age at diagnosis between major cities and regional areas, with ASD diagnosed later in regional and remote areas relative to the major cities of Australia (Bent et al., 2015). In addition, families are able to access either public, i.e. subsidized by government funding, or private services for ASD assessments. While the wait list period for private diagnostic services may be lower than for publicly-funded services, the shorter wait can be offset by the significant cost of private assessment services, which can be upwards of a thousand dollars.

Identifying ASD accurately and early is essential given that state and federal funding for early intervention is based on a formal diagnosis made before a child turns seven (Australian Government, 2015). An inaccurate diagnosis may mean that children are not eligible for early interventions that focus specifically on areas of difficulty in ASD (Prior et al., 2012). Alternatively, children who are misdiagnosed with ASD may access services that are not relevant or effective for their areas of difficulty. In addition, it is well established that early intervention improves outcomes for children with ASD (Magiati et al., 2012; Reichow et al., 2012) and that children who start intervention at a young age make more improvements than children who start at an older age (Fenske et al., 1985; Granpeesheh et al., 2009; Rogers et al., 2012). While ASD can be reliably diagnosed at two years of age (Cox et al., 1999; Moore & Goodson, 2003; Eaves & Ho, 2004), the average age of diagnosis in Australia is over four years (49 months), with ASD most frequently diagnosed at 71 months (Bent et al., 2015). Variability in the age of diagnosis has been observed between Australian states, with significantly earlier diagnosis in WA and NSW relative to all other states and territories. The variation in age at diagnosis may be associated with inconsistent diagnostic practices across the nation, with more rigorous standards, e.g. in WA, associated with earlier age at diagnosis in the state.

While two previous studies investigated diagnostic practices for ASD in Australia, that research included only paediatricians (Randall et al., in press; Skellern et al., 2005) and child psychiatrists (Skellern et al., 2005). Skellern et al. (2005) examined the assessment practices of paediatricians (N = 79) and child psychiatrists (N = 26) in Queensland, finding considerable variability in the diagnostic practices of these clinicians. The results of a more recent survey revealed similar findings. In a study of 124 paediatricians across Australia, Randall et al. (in press) found that only a minority of participating clinicians usually included information from cognitive/developmental assessments, or involved other disciplines in the diagnostic process. These practices are inconsistent with current clinical guidelines (NICE, 2011; Silove et al., 2008) for ASD diagnosis. The lack of consistent standards in Australia likely result in different diagnostic protocols and variability in the quality and accuracy of ASD diagnoses.

Purpose, Scope and Structure of this Report

In this publication, we report the outcomes of a survey of 173 health professionals whose clinical practice included participating in diagnostic assessments for ASD. While we acknowledge that many individuals on the autism spectrum, prefer not to use the term ASD, this is used in this report consistent with DSM 5 diagnostic classification (American Psychiatric Association, 2013) and the focus of this study. We aimed to survey a representative sample of health professionals covering a range of disciplines, states, and service settings. In this study, we compared diagnostic practices for ASD across the Australian states and territories and between clinicians who are experienced in the assessment and diagnosis of ASD.

This report provides detailed findings on a number of areas that are important for ASD diagnosis in Australia. These include:

- The health professionals who are currently involved in the diagnostic process for ASD.
- Diagnostic processes for ASD and how these processes vary across the nation.
- Differences in diagnostic practices across the states and territories of Australia and between the private and public service settings.
- Diagnostic outcomes across Australia in 2014-2015.
- The logistics of ASD assessment in Australia, particularly with regard to the wait list periods in the private and public sectors and the cost of assessments for families.

- ASD diagnosis in regional, rural and remote Australia.

Method

This research involved a cross-sectional survey of health professionals in Australia. Participants completed an anonymous 141-item questionnaire that was presented via Qualtrics (Qualtrics, Utah), an online survey platform. The survey questions were developed based on clinical experience and previous literature that has investigated the diagnostic practices of paediatricians in Australia (e.g. Randall et al., in press; Skellern et al, 2005). The questionnaire was developed and piloted by eight clinicians and researchers with expertise in ASD and revised based on feedback from this group prior to administration. The survey contained questions that fell into three categories: (1) diagnostic service, (2) diagnostic practice, and (3) diagnostic outcomes and took up to two hours for participants to complete (see Appendix A for full details of the survey). The survey was made available online from January to August 2015. This research was approved by the UWA Human Research Ethics Committee (Ref RA/4/1/6997).

Participants were recruited via the large network of the Cooperative Research Centre for Living with Autism (Autism CRC). The Autism CRC is a national cooperative research effort focused on ASD across the lifespan which includes universities, government agencies, service providers, Autism awareness groups and professional bodies. Information about the survey was also distributed through professional organisations such as Speech Pathology Australia, the National Rural Health Alliance, Neurodevelopmental and Behavioural Paediatric Society of Australasia, and the Western Australian Autism Diagnostician's Forum and via social media.

Statistical Analysis

The survey was designed so that respondents only responded to questions that were relevant to their clinical practice. For example, if the health professional indicated that they only conduced assessments in metropolitan areas, they were not required to answer the questions regarding assessments in regional, rural and remote areas of Australia. Therefore, there was a different response rate for each question. The data have been analysed based on the number of responses for each question rather than the total number of completed questionnaires.

All data were screened for normality prior to analysis. Nonparametric tests (Kruskal-Wallis and Mann-Whitney U) were used where the data were not normally distributed. Otherwise, continuous data were analyzed using ANOVA, with post-hoc (Scheffe' Test) comparisons used to follow up significant omnibus ANOVA results. Categorical data were analysed using the chi-square test.

Participating Health Professionals

One hundred and seventy three health professionals started the questionnaire and complete responses were obtained from 99 respondents (58%). All states and territories, as well as all disciplines included in multidisciplinary assessments for ASD were represented (see Table 1). There was a similar number of responses from the public/non-government (N = 82, 35%) and private (N = 90, 38%) sectors, with 29% of respondents working in both the public and private sectors[1].

[1] Participants who reported that they had part time employment in the public and the private sectors were asked to indicate which setting was their primary setting, i.e., where they spend more than 50% of their time. All responses were then based on the primary practice setting.

A similar proportion of the respondents worked as sole practitioners (37%) or within a multidisciplinary team[2] (39%), with 23% of respondents following 'other' models of practice, e.g., working as a sole practitioner and within a multidisciplinary team (MDT). While there was no significant difference in the proportion of practitioners working in MDTs or as sole practitioners across states, $\chi^2(7, N = 101) = 10.16$, $p = .07$, $\Phi = .32$, there was a higher proportion of MDT practitioners in the public (69%), relative to the private (35%) sector, $\chi^2(1, N = 101) = 12.21$, $p < .001$, $\Phi = .35$. In addition, a higher proportion of sole practitioners came from the private (69%) relative to the public (31%) sector.

Table 1.
Number of respondents from each state or territory of Australia, categorized by profession.

	Australian State/Territory								
	ACT	*NSW*	*NT*	*Qld*	*SA*	*Tas*	*Vic*	*WA*	**Total**
General Practice	-	-	-	-	-	-	1	-	**1**
Paediatrics	-	7	1	4	8	3	5	4	**32**
Psychiatry	-	2	1	-	-	-	-	1	**4**
Psychology	2	13	-	9	14	6	14	17	**75**
Speech Pathology	-	3	3	2	15	4	11	8	**46**
Occupational Therapy	-	1	-	2	2	-	4	-	**9**
Other*	-	2	-	1	1	1	1	-	**4**
Total	**2**	**28**	**5**	**18**	**40**	**14**	**36**	**30**	**173**

*Comprising one Manager (TAS), Researcher (QLD), Dual paediatrics/psychiatry (VIC), Autism consultant/Researcher (SA) and not specified (NSW)

Participants had been involved in ASD diagnosis for a median of 9.5 years (*SD* = 7.50 years, Range 1-30 years). Seventy-six participants (85%) had completed training in ASD assessment. Training consisted of either undergraduate or postgraduate education, supervision, case discussions or participation in courses for the administration of the Autism Diagnostic Observation Schedule (ADOS; Lord et al., 2012), Autism Diagnostic Interview (ADI; Rutter et al., 2003) or Developmental, Dimensional, and Diagnostic Interview (3Di; Skuse et al., 2004).

Diagnostic Processes

Current clinical guidelines for ASD assessment recommend that information is gathered from several sources and multiple settings (such as home, kindy, child care as well as clinic), particularly if there are discrepancies between reported behaviours and observations conducted in the clinic (NICE, 2011). Information from all sources is then used, together with clinical judgement, to make a diagnosis based on internationally recognized classification systems, currently the DSM-5 (APA, 2013) or ICD-10 (World Health Organisation, 1992). In this section, we describe the processes that Australian health professionals who responded to this survey follow when making an ASD diagnosis.

ASSESSMENT SESSIONS AND LENGTH

Respondents completed a median of 2 (Range = 1-6.5) sessions for ASD assessments with a median assessment length of 90 minutes (SD = 98.15 minutes, Range 30-600 minutes). There was no difference in the number of assessment sessions completed in the private (Median = 2, SD = 1.3, Range = 0-6.5) relative to the public (Median = 2, SD = 1.3, Range = 1-6.5) sector, U = 1072, $p = .056$. However, assessment sessions in the public sector (Median = 120 minutes,

[2] Participants who reported that they were part of a multidisciplinary assessment team were instructed to respond on behalf of the team and to have only one person from the team complete the survey.

SD = 108.8 minutes, Range = 40-600 minutes) were significantly longer than those in the private sector (Median = 90 minutes, SD = 88.6 minutes, Range = 30-420 minutes), U = 1012, p = .03.

MULTIDISCIPLINARY ASSESSMENT

MDTs (N = 52 respondents who were in MDTs) most commonly comprised one medical and two allied health professionals, usually a psychologist and speech pathologist. All of the participating occupational therapists were part of a MDT. Most MDTs (98%) conducted assessments in series, together, partially together or in collaboration, i.e. each clinician completes an independent assessment, but all assessors meet to make a consensus diagnostic decision. In contrast, sole practitioners tended to complete assessments in isolation (31%) or in series (47%), i.e. assess an individual independently one after the other. Only small numbers of the sole practitioners reported collaborating with other clinicians, with one of the 15 (7%) sole practitioners working in isolation and 4 of those working in series (17%) collaborating with external agencies.

MULTI-SETTING ASSESSMENT

Most respondents (95%) observed the individual in the clinic in all assessments (Median frequency = 100% of assessments, SD = 31%, Range = 0-100%). Assessments in the home or school/daycare settings were less frequent, with 47% of respondents including home observations (Median frequency = 0% of assessments, SD = 22%, Range = 0-100%) and 77% of respondents including observations in the school or daycare (Median frequency = 20% of assessments, SD = 31%, Range = 0-100%). Only two clinicians (2%), both from the public sector, included clinic and school/daycare observations in more than 75% of the assessments, with 12 clinicians (11%), 4 private practitioners and 8 from the public sector, completing observations in the clinic and home settings. Three respondents (3%), 2 from the private sector and one from the public sector, observed a child in the home and school/daycare settings in more than 75% of the assessments.

SUMMARY

These findings highlight variability in assessment protocols and processes across Australia. While current clinical guidelines recommend that information is gathered from multiple sources and across different settings, respondents indicated that observation of the individual in settings outside the clinic setting is infrequent. Conducting assessments across settings is likely to be expensive. However, observation of an individual only in the clinic setting may result in important information, such as peer interaction, being missed. In addition, there can be discrepancies between parent-report and actual behaviour (e.g. Ozonoff et al., 2011), which may result in inaccurate or more limited information about an individual's skills being gathered. Of concern is the lack of multidisciplinary collaboration in the private sector, particularly for sole practitioners, who tend to work in isolation and seldom liaise with other clinicians to make an ASD diagnosis. The limited multidisciplinary collaboration and lack of information obtained from multiple sources and across settings is inconsistent with current clinical guidelines for ASD assessment and diagnosis (NICE, 2011).

Diagnostic Practices

Current clinical guidelines for ASD diagnosis recommend that assessments should minimally consist of a developmental and medical history and physical examination (NICE, 2011). The assessment should also include measures that address differential diagnosis such as intellectual disability as well as observations of the child's social communication skills. The outcomes of the assessment must then be communicated to the family and the individual as appropriate. In this section, we describe the assessment measures that respondents commonly included in diagnostic assessments for ASD.

HEARING TEST

Paediatricians (N = 20) were asked to indicate how frequently they include a hearing test as part of an ASD assessment. Participants responded on a 7-point Likert Scale, which ranged from 1 (Never) to 7 (Always). Only two clinicians (10%) reported that a hearing test is included in all ASD assessments. Two paediatricians (10%) indicated that they rarely include a hearing test in ASD assessments, with five practitioners occasionally or usually (i.e. in 30-50% of assessments) completing a hearing test. A further 11 paediatricians (55%) included a hearing test frequently or usually (i.e. in 70-90%) for assessments where ASD is suspected.

MEDICAL INVESTIGATIONS

Paediatricians (N = 21) were asked how frequently they included the results of medical investigations as part of assessments for suspected ASD. Medical investigations included a genetic screen, Fragile X genotyping, neurological and physical examinations, and pathology. Fifteen respondents (71%), reported that they include medical investigations frequently or usually (i.e. in 70%-90% of their assessments), with only four paediatricians (19%) including medical investigations in all assessments where ASD is suspected. All of the paediatricians who include medical investigations in ASD assessments reported completing a genetic screen, Fragile X genotyping, and neurological and physical examinations.

ASSESSMENT MEASURES

A developmental history, i.e. to gather information about early developmental milestones, was reported to have been undertaken by 89% of respondents. One-hundred and seven participants responded to questions regarding the administration of assessment tools. Of these, 66 (62%) reported always administering standardised assessments in diagnostic evaluations for ASD, and 21 (20%) reported doing so frequently or usually (i.e. in 70-90% of ASD assessments). There was no difference between private (N = 51, 88%) relative to public (N = 36, 77%) service settings in the proportion of respondents who frequently administer assessments, χ^2 (1, N = 87) = 2.35, p = .13, Φ = .15, nor were there differences between states in the proportion of respondents who administer assessments, χ^2(7, N = 105) = 2.95, p = .71, Φ =.17.

Participants who reported administering assessments were asked to indicate which types of assessments are typically included in diagnostic evaluations for ASD. Since some measures are restricted to use by particular professions, it was unsurprising that there was variability in the proportions of clinicians administering cognitive, language and adaptive assessments and measures of ASD symptomatology (see Table 2). Only 50 respondents (47%) administered the ADOS and 41 (39%) the ADI-R, which are considered high-quality measures for ASD behavioural profiling. Thirty-two respondents (30%) used the ADOS and the ADI-R together in diagnostic evaluations for ASD. Other measures of ASD symptoms included the 3Di (n = 2), the Childhood Autism Rating Scale (n = 38), Modified Checklist for Autism in Toddlers (n = 16), Social Communication Questionnaire (n = 16), Australian Asperger Syndrome Scale (n = 10), the Autism Spectrum Rating Scale (n = 6), Childhood Autism Spectrum Test (n = 7) and Social Responsiveness Scale (n = 19), often without including an ADOS or an ADI-R.

Of the 105 respondents who indicated that they administered assessments as part of diagnostic evaluations for ASD, only 8 (8%) reported that they completed an assessment battery comprising measures of developmental, cognitive, language, adaptive skills and ASD symptomatology. The numbers increased only marginally when we examined developmental and cognitive assessments separately, with 11 respondents (10%) completing a developmental assessment in addition to measures of language, adaptive skills and ASD symptoms, and 14 (13%) completing a cognitive assessment in addition to these other measures. Taking the profession-specific assessments separately revealed that 27 Psychologists (53%) administered cognitive and adaptive assessments in addition to measures of ASD

symptomatology, and 14 Speech Pathologists (56%) administered language assessments in addition to measures of ASD symptomatology.

Table 2.
Percentage of respondents (N = 105) from each discipline who administered standardized assessments of development, cognition, language, adaptive skills or ASD symptoms. Respondents were given a list of assessments that fitted within each category, but were also able to specify other measures that they administered. Example assessments within each category are described at the foot of the table.

	Developmental	Cognitive	Language	Adaptive	ASD
Paediatrics					
(N = 21)	24%	29%	29%	19%	57%
Psychiatry					
(N = 3)	-	-	-	33%	66%
Psychology					
(N = 52)	35%	71%	29%	73%	90%
Speech Pathology					
(N = 25)	20%	20%	92%	24%	64%
OT					
(N = 3)	33%	33%	33%	67%	67%
Other					
(N = 2)	50%	-	-	50%	100%

Developmental Assessments: Griffiths, Bayley, Mullen
Cognitive Assessments: WPPSI, WISC, WAIS, Leiter, UNIT, WNV
Language Assessments: CELF, CASL, CCC-2, CC-A, PLS
Adaptive Assessments: VABS, ABAS, ABS, Scales of Independent Behaviour
ASD Assessments: ADOS, ADI, 3Di, DISCO, CARS, M-CHAT, SCQ, ASSQ, ASRS, CAST, SRS
Other Assessments: Connor's, CBCL, SDQ, BRIEF

To account for clinicians who may review the results of assessments that are administered by other disciplines, we also asked participants to indicate whether they review assessment results. Sixty-seven (68%) respondents reported that they review assessment results. There were no differences in the proportion of respondents from each profession, χ^2 (4, N = 98) = 6.29, p = .18, Φ = .18, or state, χ^2 (7, N = 98) = 2.31, p = .80, Φ = .15 who review the results of assessments. Finally, we investigated whether respondents who do not regularly administer assessments (i.e. in less than 30% of assessments), review assessment results instead. Six of the 17 respondents (35%) who do not regularly administer assessments always review assessment results. A further 3 respondents (18%) who do not regularly administer standardized assessments often review these results of assessments that have been administered in other settings.

Two respondents, both sole practitioners, reported that they do not administer standardized assessments in diagnostic evaluations for ASD. These respondents reported that they do not administer standardized measures because they are not part of everyday practice, or because they have already been administered at another service. In addition, one respondent reported that the standardized measures are not required because diagnostic decision-making is outlined in the DSM-5.

ASSESSMENT REPORT

Ninety-seven respondents (98%) indicated that they provided a diagnostic report at the conclusion of an ASD assessment. Most participating clinicians (99%) frequently, usually or always included a clinical and developmental history, summary of the assessment process, assessment outcomes, results of specific assessment tools, statement of the diagnosis, and

recommendations in assessment reports. Respondents who reported that they do not provide a diagnostic report indicated that the report is completed by another health professional.

SUMMARY

Best practice guidelines for ASD assessment and diagnosis recommend that an assessment should consist of a full medical evaluation, developmental or cognitive assessment, an assessment of language and adaptive skills and incorporate standardized measures of ASD symptomatology (Anagnostou et al., 2014; Filipek et al., 2000; NICE, 2011). The results of this survey indicate that, in practice, diagnostic assessments that include all of these components are rare.

While medical investigations, such as a hearing test, physical examination, genetic microarray and Fragile X test are recommended as part of an ASD assessment, these tests are not always conducted, with only 19% of participating paediatricians including medical investigations in all ASD assessments. In addition, only 10% of participating paediatricians included a hearing test in all ASD assessments. However, each Australian state and territory does run a universal newborn hearing screening program (Australian Hearing, 2014), so paediatricians may rely on results from previous medical investigations to inform an ASD assessment. Nevertheless, the current findings are consistent with the results reported by Randall et al. (in press), who found that only a minority of Australian paediatricians follow current investigation recommendations for diagnosing ASD.

The current findings also indicate that the inclusion of measures of cognition, language and adaptive skills is inconsistent, differing across services and disciplines. However, these assessments are necessary for the differential diagnosis of ASD from other neurodevelopmental and behavioural disorders, as outlined in the DSM-5 (APA, 2013). In addition, while current 'gold standard' measures of ASD symptoms include the ADOS and the ADI-R, only three quarters of the respondents regularly administered these assessments. Of these participants who administer assessments of ASD symptomatology, 30% reported using the ADOS and the ADI-R in diagnostic evaluations for ASD, despite evidence indicating that these measures enhance the sensitivity and specificity of ASD diagnoses when administered together (Risi et al., 2006). This finding could not be accounted for by review of assessments conducted by external professionals as only 68% of respondents reported reviewing assessment results obtained from other settings.

Comprehensive diagnostic assessments for ASD that comprise all elements included in best practice guidelines are lengthy and expensive. It is possible that the time required to administer standardized assessments and measures of ASD symptomatology as well as conducting observations of the individual across settings is prohibitive for practitioners. Nevertheless, the reduced time taken to complete the assessment may result in practices that fall short of best practice standards.

Diagnostic Outcomes

Respondents were asked to provide an indication of the number of assessments completed in their service in the 12 months prior to completing the survey. Participants also provided an approximate number of the assessments that had resulted in ASD diagnoses. We asked participants how they approached diagnostic uncertainty, specifically, whether they assign provisional diagnoses, or whether they have diagnosed ASD when an individual does not meet criteria for the disorder (diagnostic upgrading). These results are detailed in the following section.

ASD DIAGNOSIS

Ninety-one of the 92 respondents (99%) were using the DSM-5 to make diagnoses, with the remaining participant using the DSM-IV.

The diagnosticians had participated in 6960 (Median = 38, SD = 76.43, Range = 4-400) ASD assessments in 2014-2015. Overall, respondents had made 4037 ASD diagnoses in the 12 months prior to the survey. Therefore, across the whole sample, 58% of the diagnostic assessments (4037/6960) had resulted in an ASD diagnosis in 2014-2015.

While there was substantial variability in the percentage of assessments resulting in an ASD diagnosis between the states (see Figure 1), this difference was not significant, $\chi^2(7) = 7.46$, $p = .38$. There was a significantly higher rate of ASD diagnosis in the private (Median = 80%, SD = 14.59, Range = 40-100%) compared to the public (Median = 70%, SD = 18.46, Range = 22-95%) sector, U = 826, p = .018 and for sole practitioners (Median = 78%, SD = 16.2%, Range = 22-100%) relative to MDTs (Median = 70%, SD = 17.3% , Range = 22-95%), U = 457.5, $p = .038$.

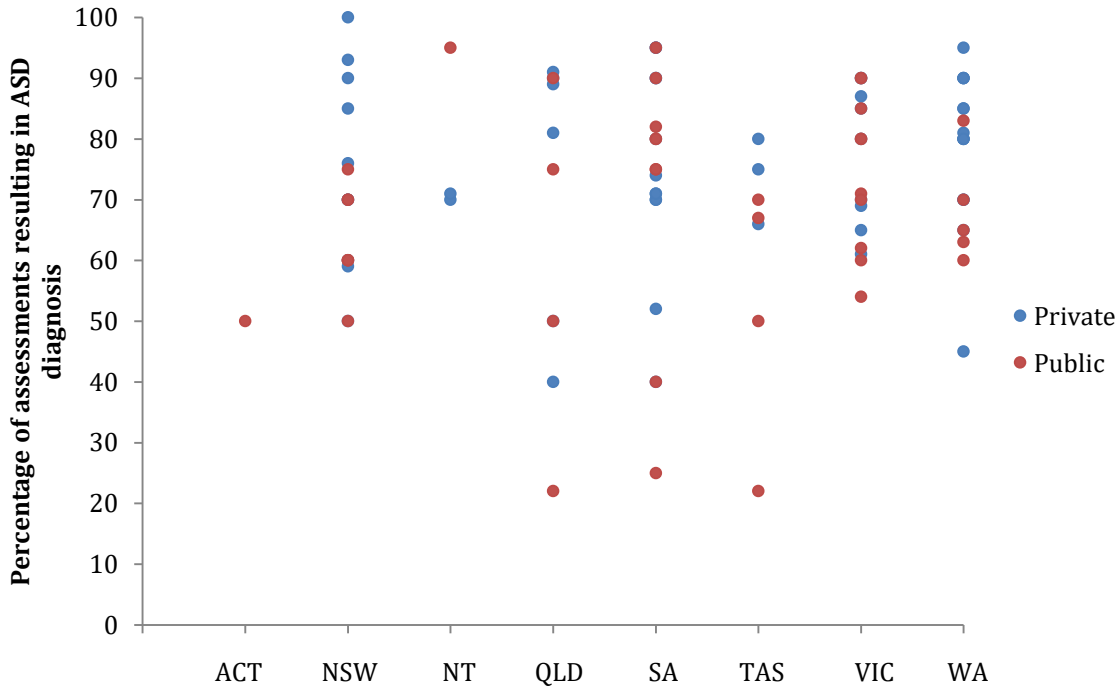

Figure 1. Percentage of assessments resulting in an ASD diagnosis in each Australian state and in the private and public service settings.

SOCIAL (PRAGMATIC) COMMUNICATION DISORDER (SCD)

Only 166 assessments (2.39%) resulted in a SCD diagnosis within the last 12 months, with a mean of 1.95 (SD = 3.32, Range = 0-15) SCD diagnoses per service. There was no difference in the proportion of SCD diagnoses by state, $\chi 2\ (7) = 7.26$, $p = .4$. Of the 44 respondents who reported that they had diagnosed SCD, 28 (63.64%) indicated that the child/ren would have

met DSM-IV criteria for ASD, most commonly Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS).

FAMILIES SEEKING ASD DIAGNOSIS

Seventy-seven respondents (82%) reported that families have visited their diagnostic service after having a previous assessment that did not result in an ASD diagnosis. However, most of these respondents reported that this happens rarely (57% of respondents) or occasionally (31% of respondents). The reasons that families may seek a second assessment included the child being very young (n = 44), the child not having an ASD (n = 45) or for complex assessments (n = 55). Respondents indicated that a median of 50% of these assessments (Range = 0-100%) result in an ASD diagnosis in their service.

RESPONDING TO DIAGNOSTIC UNCERTAINTY

Participants responded to two series of questions regarding their response to diagnostic uncertainty. The first series of questions asked about provisional diagnoses, which can be made when ASD is suspected but not confirmed, perhaps due to the young age of the child. These diagnoses needed to be reviewed within a pre-determined time interval, or after more information had been gathered. Respondents were also asked to indicate whether they have ever made an ASD diagnosis when an individual does not meet criteria for the disorder. Making these types of diagnoses is known as diagnostic 'upgrading' and has been identified among clinicians diagnosing behaviourally-based disorders in the UK, the US and Australia (Rogers et al., 2015; Rushton et al., 2002; Skellern et al., 2005).

Forty-seven respondents (48%) reported that they make provisional ASD diagnoses when faced with diagnostic uncertainty. There was no difference in the proportion of provisional diagnoses between private and public settings, χ^2 (1, N = 97) = 2.53, p = .11, Φ = .16, or across the states, χ^2 (7, N = 97) = 12.8, p = .08, Φ = .36. Of the respondents who made provisional diagnoses, 34 (72%) reported that this label is rarely used, with the remaining 5 (11%) and 2 (4%) reporting that provisional diagnoses were given occasionally and sometimes respectively. Provisional diagnoses were reportedly given when individuals demonstrated subthreshold symptoms, were very young, or in their opinion would benefit from intervention. Thirty-nine respondents (83%) reported that they re-assess individuals with provisional diagnoses within a mean of 13 months (SD = 7.96 months).

Sixteen respondents (17%) reported that they have diagnosed ASD when the person did not meet full criteria for the condition. Fifteen of these respondents (88%) reported that this had occurred rarely (i.e. in less than 10% of their assessments), with the remaining respondents indicating that it had been occasional (about 30% of assessments). While there was no significant difference in the proportion of upgrading coming from each state, χ^2 (7, N = 94) = 2.41, p = .79, Φ = .16, a significantly higher proportion of respondents who made a diagnosis when the individual did not meet criteria came from the private (81%) relative to the public (19%) sector, χ^2 (1, N = 94) = 4.50, p = .035, Φ = .22. When asked about the reasons for making the ASD diagnosis, 14 (88%) clinicians reported that they thought that the individual did have ASD, but that the assessment did not represent the individual's usual presentation. Other commonly reported reasons for the diagnosis were to ensure that the child could access early intervention (n = 6), school support (n = 5) or disability services (n = 3).

SUMMARY

In 2014-2015, 58% of the assessments completed by participating health professionals resulted in an ASD diagnosis. Only a small number of health professionals reported that they have diagnosed SCD. Approximately two-thirds of the clinicians who had diagnosed SCD indicated that these children would likely have met DSM-IV criteria for PDD-NOS. These results are

consistent with empirical findings, which indicate that the DSM-5 may under-identify those with subthreshold ASD symptoms who would have previously been diagnosed with PDD-NOS. Evidence from the literature also indicates that there is a subgroup of children who present with significant social communication deficits, who may not meet diagnostic thresholds for ASD. Indeed, Mandy et al. (2011) found that 97% of their sample of children with PDD-NOS displayed social communication deficits which were of comparable severity to children with Autistic Disorder or Asperger's Disorder.

Higher proportions of assessments from the private sector resulted in ASD diagnoses than those in the public sector. Also, a higher proportion of ASD diagnoses were reported by sole practitioners compared to health professionals from a MDT. However, the accuracy of ASD diagnosis by sole practitioners may be lower than for those conducted by MDTs given; (1) the higher reported frequency of upgrading diagnoses, (2) less frequent use of standardized assessments, (3) less access to information from multiple settings, and (4) less frequent collaboration with other disciplines. One recent study in the United States compared the diagnoses of individual clinicians to those resulting from a transdisciplinary assessment team (Stewart et al., 2014). The results showed that 65% of the individual clinicians matched the transdisciplinary diagnoses, with ASD missed in 29% of cases and over-diagnosed in 37% of cases. These findings indicate that clinicians acting independently do not make the same diagnoses as multidisciplinary diagnostic teams. In addition, collaboration across disciplines may result in more accurate diagnoses of ASD and other neurodevelopmental and behavioural disorders.

A small proportion of respondents (17%) reported that they have diagnosed ASD when a person does not meet criteria for the disorder. Clinicians who had diagnosed an individual with ASD when the person did not meet criteria for the disorder were more likely to come from the private sector than the public sector. The majority of these respondents had made the diagnosis when they felt that the person did have ASD, but that the assessment did not represent the person's usual presentation, perhaps due to limited information from settings outside the clinic.

The other frequently reported reasons for making the diagnosis when an individual did not meet full criteria for the disorder were to ensure that the person could access early intervention, support at school or access other disability services. These findings are consistent with previous research that has investigated the diagnostic practices of clinicians in Queensland, the United States and the United Kingdom (Rogers et al., 2015; Rushton et al., 2002; Skellern et al., 2005). Rushton et al. (2002) reported that 14% of physicians had increased the level of diagnosis or severity, most commonly because of a lack of diagnostic certainty, but also to ensure that the individual could access services and financial aid. In Queensland, over half of the surveyed paediatricians and psychiatrists reported providing an ASD diagnosis when faced with diagnostic uncertainty, either for educational ascertainment, or to access sources of funding (Skellern et al., 2005). In a more recent survey of professionals in the United Kingdom, Rogers et al., (2015) also found that 55% of the participating respondents had practiced diagnostic upgrading, albeit infrequently. These respondents commonly upgraded the diagnosis so that the individual could access support in the health or school sectors, or because there were differing opinions within the diagnostic team (Rogers et al., 2015). These findings indicate that in the face of diagnostic uncertainty, clinicians are more likely to make a diagnosis than not. The intentional ascription of an inaccurate diagnosis to facilitate access to services may contribute to the increased diagnostic rates over time. Indeed, Nassar et al. (2009) found that the increased incidence of ASD in WA was related to changes in diagnostic practices and service provision in this state. These findings highlight the complexity of ASD diagnosis and the challenges associated with funding being designated according to diagnosis rather than need.

The Logistics of ASD Diagnosis in Australia

Anecdotal evidence obtained from families indicates that the wait for an ASD assessment in Australia is long and the cost of an assessment is high. In this section, we describe the wait list periods and cost of an ASD assessment reported by participating health professionals.

ASSESSMENT WAIT

While the median wait list period across the nation was 6 weeks, there was considerable variability across states (Range = 1 – 108 weeks). Five services - 2 in Victoria and 3 in WA - all from the private sector, reported wait list times of 1 week. Wait times of more than 12 months were reported for services in South Australia (n = 2), Tasmania (n = 1), Victoria (n = 3) and for other WA services (n = 2). There was no significant difference in the wait time for an assessment between states, $\chi 2$ (7) = 4.41, p = .73.

The wait-list period for an ASD assessment was significantly longer in public/NGO (Median = 16 weeks, SD = 20 weeks, range = 2-108 weeks) relative to private (Median = 4 weeks, SD =15.5 weeks, Range = 1-52 weeks) settings (U = 581, p < .001) (see Figure 1). The wait for a MDT assessment (Median = 12 weeks, SD = 25.75, Range = 1.5-108 weeks) was also longer than for a sole practitioner (Median = 4 weeks, SD = 9.84, Range = 1-52), Mann-Whitney U = 511, p = .005, perhaps due to the higher number of MDTs in the public sector relative to the private sector, which this report has found takes more time than sole practitioner assessments.

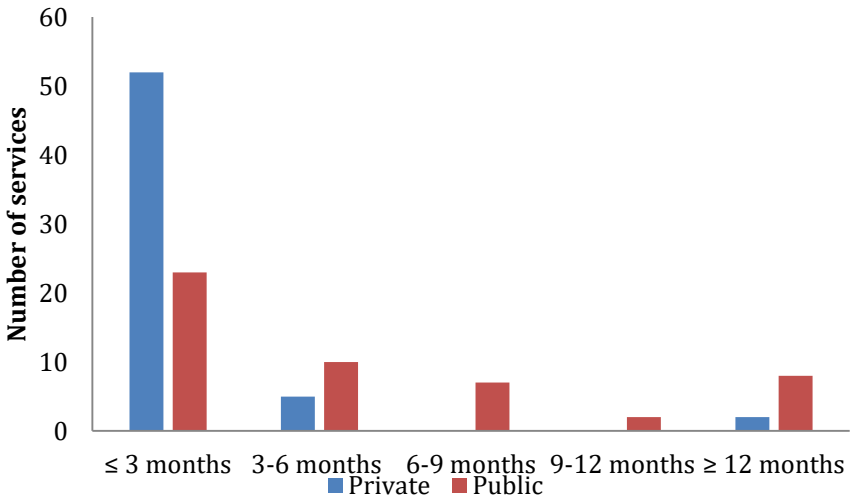

Figure 2. Total number of public and private services which have wait-list periods of less than three months to over 12 months.

ASSESSMENT COST

Respondents were asked to state the cost of an ASD assessment in their service. Respondents typically described the cost of the assessment for families. Health professionals in the private sector often elaborated on this response by saying that Medicare Benefits for ASD assessments are available through the HCWA package. Public services and Non-Government Organisations (NGO) were grouped together throughout the survey, so a number of the points designated as “public” in the graph represent the cost of the assessment in an NGO, which may charge a nominal fee to families.

Across all services, the median cost of an ASD assessment for families was $580 (SD = $599.47). However, there was considerable variability in the assessment costs across states and service settings (Range = $0 - $2750) (see Figure 3).

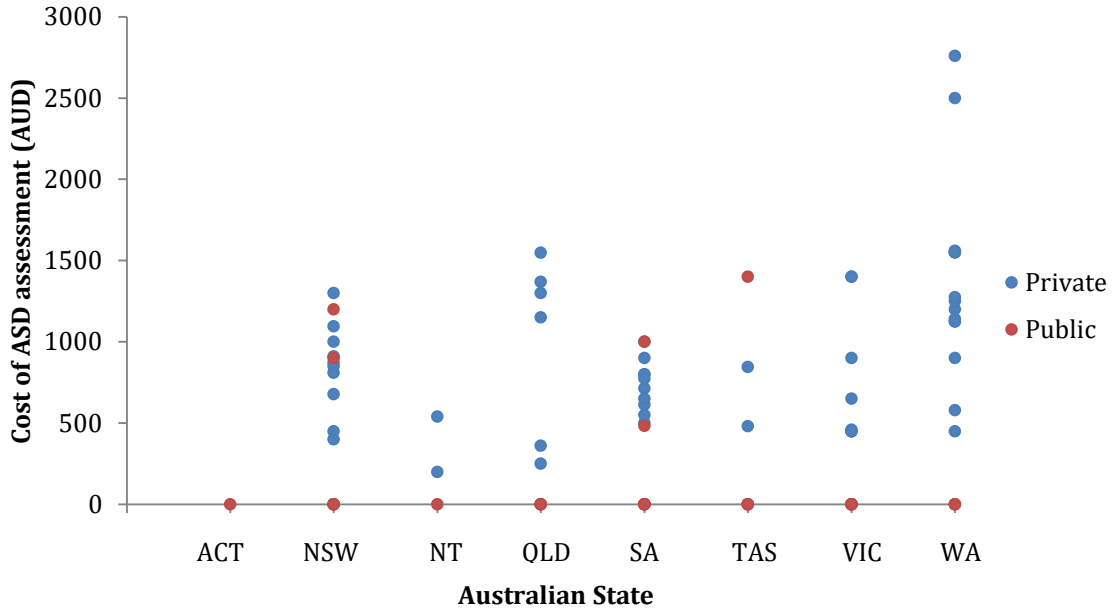

Figure 3: Cost of an ASD assessment for families in each Australian state/territory and across the public and private service settings.

SUMMARY

These results highlight variability in the waiting time for an ASD assessment, particularly between the private and public service settings. Current clinical guidelines recommend that ASD diagnostic assessments start within three months of referral to an Autism team (NICE, 2011). While a large number of private services have wait list periods of less than three months, the wait time for an ASD assessment in the public sector can be up to two years. Similar wait list times have been reported in the UK, where the results of a recent study revealed delays of up to 3.5 years between the parents' initial contact with a health professional and the child being formally diagnosed with ASD (Crane et al., 2015). Longer delays between the identification of atypical development and the final diagnosis were significantly associated with lower parental satisfaction with the diagnostic process. Interestingly, the long wait list periods reported in our study tended to occur within the public sector, where assessments were more likely to be conducted by a MDT. While the long wait list periods, particularly in the early years, may impede access to early intervention, the waiting time may also be associated with a more comprehensive diagnostic assessment.

The cost of an ASD assessment also varies considerably across Australia. The substantial cost of an ASD assessment, particularly in the private sector, contributes to the lifelong financial burden experienced by families of individuals with ASD, with research from Australia and the United Kingdom indicating that the cost of supporting individuals with ASD is £0.8 million per annum (Knapp et al., 2009), with the cost per individual increasing with the severity of the disability (Horlin et al., 2014). While the cost of an assessment for families in Australia is higher in the private sector than in the public sector, the higher cost may be offset by shorter waiting times. Therefore, assessments in the private sector, while costly, may expedite access to funding and services for these families. While families who can afford a private assessment may seek this out to facilitate access to early intervention, the expedited assessment process may compromise best practice in ASD diagnosis (e.g., by reduced multidisciplinary collaboration or the exclusion of observations across settings). These findings highlight the challenge of balancing wait list times, assessment costs and assessment quality.

Diagnosis in Regional, Rural and Remote Australia

Eighty-five health professionals (56%) reported that they were based in metropolitan regions, with 35 in regional, rural or remote areas (23%). Thirty-two health professionals (21%) reported that they conducted diagnostic assessments for ASD in major cities and in regional, rural and remote areas of Australia (see Table 3).

Table 3.
Number of respondents from each profession and each state/territory of Australia who conduct ASD assessments in regional, rural or remote areas.

	State/Territory of Australia								
	ACT	*NSW*	*NT*	*Qld*	*SA*	*Tas*	*Vic*	*WA*	**Total**
Paediatrician	-	3	1	2	2	2	3	0	**13**
Child Psychiatrist	-	-	-	-	-	-	-	-	**-**
Adult Psychiatrist	-	-	-	-	-	-	1	-	**-**
Psychologist	2	5	-	3	3	6	1	6	**26**
Speech Pathologist	-	2	2	-	9	2	1	6	**22**
Occupational Therapist	-	1	-	-	1	-	1	-	**3**
Other	-	1	-	1	-	-	-	-	**2**
Total	**2**	**12**	**3**	**6**	**15**	**10**	**7**	**12**	**67**

Participants were asked to indicate the percentage of their assessments that come from each area of Australia (see Figure 4)[3]. The results revealed that the majority of ASD assessments are conducted for families in major cities, with very few clinicians providing diagnostic services to families in remote and very remote regions of Australia.

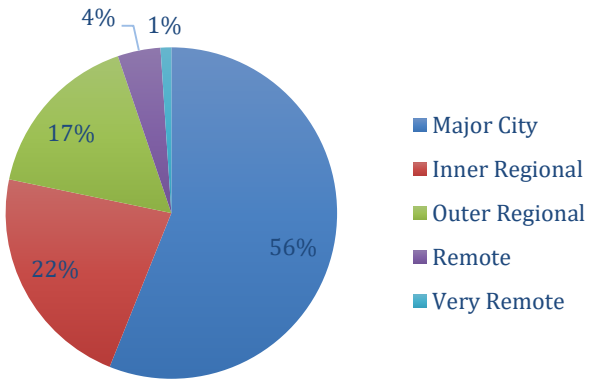

Figure 4. Mean percentage of assessments completed for families in major cities, inner regional, outer regional, remote and very remote areas of Australia.

The frequency of assessments conducted in each of the ARIA categories differed across the states and territories, with a higher percentage of assessments in outer regional, remote and very remote areas reported for the NT (see Table 4). In addition, families in regional areas of Australia wait for a median of 13 weeks (SD = 21 weeks, Range = 2-104 weeks) for an assessment in their local area. The wait for an assessment in regional, rural and remote areas of Australia was significantly longer than it was in major cities, U = 587, *p* = .02.

[3] The Accessibility/Remoteness Index of Australia (ARIA) was used as a measure of remoteness.

Table 4. Mean percentage of ASD assessments conducted in major cities, inner regional, outer regional, remote and very remote areas of Australia, for each state and territory.

	Major City	Inner Regional	Outer Regional	Remote	Very Remote
ACT	40%	58%	2%	0%	0%
NSW	50%	28%	21%	2%	.7%
NT	0%	0%	60%	10%	30%
Qld	54%	26%	11%	8%	1%
SA	72%	11%	11%	6%	.5%
Tas	7%	30%	60%	3%	0%
Vic	61%	25%	11%	0.3%	0%
WA	60%	23%	9%	4%	1%

SUMMARY

Families living in regional, rural and remote areas of Australia face barriers to accessing health care. Those who are seeking ASD assessments experience wait list periods that are twice as long as families living in the major cities of Australia, unless they travel to metropolitan clinics. The long wait lists are likely to be driven by the smaller number of medical professionals experienced in ASD assessment who are conducting diagnoses in regional, rural and remote areas of the nation.

Limitations

The number of participants who completed the survey (N = 99) was much lower than the number who started (N = 173). The low completion rate likely reflects the length of the questionnaire, which could take up to two hours to complete. While the sample size in this study was small, the number of respondents was similar to that reported by Rogers et al. (2015), who included a sample of 116 participants in a recent survey of diagnostic practices in the UK. Although our sample had representatives from all states and relevant professions, the number of respondents was not consistent across disciplines. In addition, respondents in this study were self-selected, perhaps because of a strong interest in good diagnostic standards, so the results may not represent the broader population of diagnosticians in Australia.

Conclusion

This report presents the findings of the first investigation of ASD diagnostic practices for a range of health professionals across Australia. The results revealed inconsistencies in ASD assessment practices across the states/territories, and between the private and public service settings. Furthermore, the results indicate that some clinicians in Australia may not be practicing in a manner that is consistent with international best practice guidelines (e.g., NICE, 2011) or statements from Australian professional bodies (e.g. Silove et al., 2008) for ASD assessment and diagnosis.

While some Australian states have established rigorous standards for ASD assessments (such as WA), there is currently no minimal national standard for ASD diagnosis. The variability in diagnostic practices of ASD across the nation, as well as assessments that are inconsistent with best practice guidelines may contribute to poor quality assessments, possible delayed diagnosis and access to intervention services. Conversely, assessments that more closely resemble current clinical guidelines for ASD diagnosis may be associated with longer wait list times and lower rates of ASD diagnosis. In addition, findings regarding the possible over-diagnosis of ASD have implications for service delivery, particularly when funding and service provision is determined based on diagnosis. These findings highlight the need for a consistent

national standard in ASD diagnosis, to ensure an equitable process for individuals with ASD and their families across the country.

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Appendix A: Survey of Diagnostic Practices for Autism Spectrum Disorder in Australia

With no established biomarker for Autism Spectrum Disorder (ASD), 'gold standard' diagnosis relies on a 'best estimate' clinical judgement based on the behavioural presentation of the individual. However, the variability in early ASD symptoms and the considerable behavioural overlap with other developmental disorders means that ASD diagnosis is a complex undertaking. The task of providing ASD diagnosis in Australia is further complicated by significant variability in assessment process between clinicians and between states.

This research has been co-funded by the Co-Operative Research Centre for Living with Autism Spectrum Disorders (Autism CRC) and the Australian Government Department of Social Services (DSS). The aim of the project is to conduct a comprehensive survey of diagnostic practices for ASD across Australia, in order to establish a baseline of current assessment processes. We are hoping to include clinicians from each state and territory of Australia. We hope to cover the range of professional disciplines that are currently involved in ASD assessment, including General Practitioners, Paediatricians, Psychiatrists, Psychologists, Speech Pathologists and Occupational Therapists. We would also like to include participants from metropolitan, regional, rural and remote areas of Australia, and clinicians working in the public and private sectors. This project is an essential first step towards developing national standards for ASD diagnosis and may inform Government decision making around early intervention programmes and support.

What does participation in the research project involve?

If you choose to participate, you will be asked to complete a survey which asks about your involvement in conducting diagnostic assessments for ASD. Items in the survey cover topics such as the demographic characteristics of the individuals that you assess for ASD, the diagnostic process in your service, the types of assessment tools you implement during the diagnostic process, the length that an ASD diagnosis takes, the overall cost of an ASD diagnosis and the services that an individual may be eligible for following an ASD diagnosis. The survey contains 141 questions and will take approximately 30-60 minutes to complete.

What will happen to the information collected?

Electronic data will be stored in a secure database. Any paper questionnaires will be stored securely in a locked filing cabinet in the School of Psychology at the University of Western Australia. Each participant will be identified using a unique code and no identifying information will be stored with the data. The data will only be accessed by members of the research team.

At the end of the survey, we may ask you to indicate your willingness for the research team to contact you to gather further information related to this project. If you provide consent for future contact, we will then ask you to provide identifying information, such as your name, telephone number and email address. In the event that you provide this information, all of your responses to the survey, as well as your contact details, will remain confidential. If you choose not to provide consent for future contact, all of your responses to the survey will remain anonymous.

A report outlining the results of the study will be prepared and submitted to the Autism CRC and DSS. The findings may also be prepared for submission to a journal. Your identifying information will not appear in either case.

Are there any risks associated with participation?

There are no foreseeable risks associated with participation in this project.

How do I indicate my willingness to be involved?

We hope that you will support this research. Participation is entirely voluntary, so you are free to decline without prejudice. If you decide to participate, you can change your mind at any time, without giving any reason and without any consequences.

Consent

If I select the option below to proceed to the survey, I confirm that I have read the information provided and any questions I have asked have been answered to my satisfaction. I agree to participate in the study realising that I may withdraw my consent at any time without reason and without prejudice.

I understand that all information provided is strictly confidential and will not be released by the investigator. The only exception to this principle of confidentiality is if documents are required by law. I have been advised as to what data is being collected, what the purpose is, and what will be done with the data upon completion of the research.

I agree that research data gathered for the study may be published provided my name or other identifying information is not used.

Proceeding with this survey will indicate your consent to participate in the research.

Completing the Survey

This survey includes several question types. Some questions will ask you to enter a number, and other questions use a slider. Where questions ask for a number response, we ask that you provide as accurate information as you are able. Please respond to these questions using a number (10) rather than a word (ten). If you are unable to provide an exact response, please give an approximation. In some instances, if you are unsure of the answer, you can write that you don't know. Questions that use a slider format will ask for a percentage response, e.g. "In what percentage of your assessments do you use the ADOS-G?" You must respond to all options on the slider and if the answer is 0, you just click on the bar to select 0. The survey will remain open for one week. If you do not finish the survey in one sitting, you are able to return to it at a later time and your previous responses will be unchanged. After one week, the survey will close and you will no longer be able to return to it and make further changes. Thank you for taking the time to complete this survey.

Background Information

The first series of questions will ask about your involvement in the diagnostic process for individuals with suspected ASD. There are many different ways in which professionals participate in a diagnostic assessment for ASD. If you are a sole or private practitioner and conduct diagnostic assessments for ASD independently of other clinicians, please respond on your own behalf. If you work as part of a service that conducts team assessments for ASD, or part of a practice that has a central point for taking referrals, please respond on behalf of the service.

If you are part of a multidisciplinary team, please have only ONE person from that team respond to this questionnaire. Please indicate below your basis for responding to this survey.

❍ On my own behalf (1)
❍ On behalf of my service (2)

In which state/territory do you currently practice?
❍ Australian Capital Territory (1)
❍ New South Wales (2)
❍ Northern Territory (3)
❍ Queensland (4)
❍ South Australia (5)
❍ Tasmania (6)
❍ Victoria (7)
❍ Western Australia (8)

What is your profession?
❍ General Practitioner (1)
❍ Paediatrician (2)
❍ Child Psychiatrist (3)
❍ Adult Psychiatrist (4)
❍ Psychologist (5)
❍ Speech Pathologist (6)
❍ Occupational Therapist (7)
❍ Other (please specify) (8) _____

In which of the following service settings to do you practice? (Tick all that apply)
❍ Private (1)
❍ Public, including NGO (2)
❍ Both public and private (3)

Which of the following settings best describes your service?
❍ Hospital (1)
❍ Government (2)
❍ NGO (3)

Are you currently involved in the assessment process for ASD?
❍ Yes, I refer individuals with possible ASD for assessment
❍ Yes, I conduct ASD assessments
❍ Yes I act as both a referrer and assessor
❍ No

Location of Service
These questions will ask about the location of your primary practice and the regions of Australia for which you provide diagnostic assessments.

In which areas of Australia do you conduct diagnostic assessments for ASD? (Tick all that apply)
❍ Metropolitan
❍ Regional, Rural or Remote
❍ Other (please describe) _____

What is the postcode of your primary practice setting (i.e. where you spend more than 50% of your working time)?

What percentage of the individuals that you assess come from each of the following areas of Australia? (See map below for definitions). Total must sum to 100.
_____ Major city
_____ Inner regional
_____ Outer regional
_____ Remote
_____ Very remote

Diagnostic Assessments in Regional, Rural, or Remote Areas of Australia
This series of questions ask specifically about diagnostic assessments for ASD for families who live in regional, rural and remote areas of Australia. Please consider only these families when responding to this set of questions.

What is the approximate radius (in km) of the region that you provide ASD assessment for?
❍ 50km
❍ 50km- 100km
❍ 100km - 150km
❍ 150km - 200km
❍ 200km - 250km
❍ 250km - 300km
❍ 300km -350km
❍ 350km - 400km
❍ 400km - 450km
❍ 450km - 500km
❍ More than 500km
❍ We provide a diagnostic service to the whole state/territory

In which of the following ways do families access your service?

	NA	Never	Rarely	Occasionally (about 30% of cases)	Sometimes (about 50% of cases)	Frequently (about 70% of cases)	Usually (About 90% of cases)	Always
Families travel to metropolitan clinics	❍	❍	❍	❍	❍	❍	❍	❍
Clinicians travel to regional areas	❍	❍	❍	❍	❍	❍	❍	❍
Clinicians based solely in regional area	❍	❍	❍	❍	❍	❍	❍	❍
Families travel to regional clinic	❍	❍	❍	❍	❍	❍	❍	❍
Other (please describe)	❍	❍	❍	❍	❍	❍	❍	❍

Approximately what percentage of the families that you assess travel for each of the following durations to access your metropolitan service? Total must sum to 100.
_____ Less than one hour
_____ 1 - 2 Hours
_____ 2 - 3 Hours
_____ 4 - 5 Hours
_____ More than 5 hours
_____ I travel to family homes

Approximately what percentage of the families that you assess travel for each of the following durations to access your regional service? Total must sum to 100.
_____ Less than one hour
_____ 1 - 2 hours
_____ 2 - 3 hours
_____ 4 - 5 hours
_____ More than 5 hours
_____ I travel to family homes

How long do families currently wait for an assessment from your service in their local area?

Approximately what percentage of the individuals that you assess fall in each of the following age brackets? (Total must sum to 100)
_____ 0 - 12 months
_____ 1 - 2 years
_____ 2 - 3 years
_____ 3 - 4 years
_____ 4 - 5 years
_____ 5 - 8 years
_____ 8 - 12 years
_____ 12 - 18 years
_____ 18 - 25 years
_____ 26 - 60 years
_____ More than 60 years

What type of financial assistance is available to families that travel long distances to access a diagnostic assessment for ASD? (Tick all that apply)
❍ Patient Assisted Travel Scheme
❍ Unsure
❍ Other (please describe) _____
❍ Not applicable (please specify) _____

Diagnostic Service
This series of questions will ask for details about your diagnostic service and the team that you work in.

How do you currently provide a diagnostic service for individuals with suspected ASD?
❍ As a sole practitioner
❍ As part of a multidisciplinary team
❍ Other (please describe) _____

What type of service do you provide?
❍ General developmental assessment
❍ Only ASD assessments
❍ Other (please describe) _____

Which of the following professionals are included in your multidisciplinary team? (Select all that apply)
❍ Paediatrician
❍ Child Psychiatrist
❍ Adult Psychiatrist
❍ Psychologist
❍ Speech Pathologist
❍ Occupational Therapist
❍ Other (please describe) _____

How does your assessment service work?
❍ In isolation, e.g. professionals conduct the assessment without any interdisciplinary input
❍ Together, e.g. all professionals see the individual together
❍ Partially together, e.g. team receives referral from medical professional and then allied health professionals conduct the assessment together
❍ In series, e.g. each clinician conducts the assessment independent of the others
❍ In collaboration, e.g. each clinician conducts an independent assessment, but all assessors meet to make a consensus diagnostic decision.
❍ Other (please describe) _____

Do you collaborate with professionals external to your service to make a diagnostic decision?
❍ Yes
❍ No

In what percentage of your assessments do you collaborate with external agencies/professionals?
_____

What percentage of the professionals that you collaborate with come from the following types of services? (Total must sum to 100)
_____ Sole practitioner (Medical)
_____ Sole practitioner (Psychology)
_____ Sole practitioner (Speech Pathology)
_____ Sole practitioner (Occupational Therapy)
_____ Multidisciplinary team (e.g. Psychologist and Speech Pathologist)
_____ School/day care staff
_____ Other (please describe)

How do you collaborate with these clinicians to make a diagnostic decision? (Tick all that apply)
❍ By phone
❍ Via email
❍ By video conference
❍ Face-to-face meeting
❍ Mail reports to coordinating clinician
❍ Other (please specify) _____

Are there circumstances in which you would not conduct a multidisciplinary team assessment for ASD?
❍ Yes
❍ No

In which of the following circumstances would you not conduct a multidisciplinary team assessment? (Tick all that apply)
❍ Not part of general practice
❍ Individual too young
❍ Individual too old
❍ Clinicians not available
❍ Individual has had a partial assessment from another diagnostic service
❍ Other (please describe) _____

What percentage of your diagnostic assessments co-ordinated by each of the following professionals? (Total must sum to 100)
_____ Sole practitioner (Medical)
_____ Sole practitioner (Psychologist)
_____ Sole practitioner (Speech Pathologist)
_____ Sole practitioner (Occupational Therapist)
_____ Referring clinician
_____ Multidisciplinary team (Allied Health Professionals)
_____ Other (please describe)

Ideal Assessment process for ASD diagnoses

In your opinion, what does an ideal diagnostic assessment for ASD involve?

What percentage of your diagnostic assessments resemble the ideal that you have described?
_____

Describe why an ideal ASD assessment is not always achieved?

Demographics of Individuals Assessed for ASD
This series of questions asks about the age of the individuals that you provide diagnostic assessments for.

Approximately what percentage of the individuals that you assess fall in each of the following age brackets? (Total must sum to 100)
_____ 0 - 12 months
_____ 1 - 2 years
_____ 2 - 3 years
_____ 3 - 4 years
_____ 4 - 5 years
_____ 5 - 8 years
_____ 8 - 12 years
_____ 12 - 18 years
_____ 18 - 25 years
_____ 26 - 60 years
_____ More than 60 years

Diagnostic Assessments for ASD
This series of questions will ask about the number of referrals that you have received for assessment over the past 12 months, as well as the number of assessments that you have conducted in the same period of time. Please leave blank ONLY if you are unable to obtain this information from within your service.

How frequently do you receive referrals from each of the following sources?

	Never	Rarely (< 10% of referrals)	Occasionally (about 30% of referrals)	Sometimes (about 50% of referrals)	Frequently (about 70% of referrals)	Usually (about 90% of referrals)	Always
General Practitioner (GP)	❍	❍	❍	❍	❍	❍	❍
Paediatrician	❍	❍	❍	❍	❍	❍	❍
Psychiatrist	❍	❍	❍	❍	❍	❍	❍
School	❍	❍	❍	❍	❍	❍	❍
Family	❍	❍	❍	❍	❍	❍	❍
Allied health professional	❍	❍	❍	❍	❍	❍	❍
Other (please specify)	❍	❍	❍	❍	❍	❍	❍

Once a family has been referred to your diagnostic service, how long (in weeks) do they currently wait for the initial assessment appointment?

How many referrals for assessment have you/your service received in the past month?

How many referrals for assessment have you/your service received in the past 12 months?

Of the referrals that you have received in the past 12 months, what percent (approximately) have requested an ASD assessment specifically?

How many assessments have you/your service conducted in the past month?

How many assessments have you/your service conducted in the past 12 months?

Assessment Process
This series of questions asks about the assessment processes that you have adopted within your diagnostic service.

On how many occasions do you typically see an individual for assessment prior to making a final diagnosis?

On average, how long does each assessment session last (in minutes)?

In what percentage of your assessments do you observe the individual in each of the following locations?
_____ In the clinic
_____ In the family home
_____ At school/day care
_____ I review observation reports compiled by other professionals
_____ Other (please specify)

What percentage of your assessments involve each of the following informants?
_____ Primary caregiver
_____ Secondary caregiver
_____ Other relative, e.g. grandparent
_____ School teacher/child care provider
_____ Psychologist
_____ School psychologist
_____ Other allied health professional (please specify)
_____ Other (please specify)

In your service, how long (average number of weeks) does a typical ASD assessment take, from the initial appointment to the completion and delivery of the final report to the family?

Assessment Measures
This block of questions asks about the tools that you administer or review in diagnostic assessments for ASD.

How frequently do you order or review a hearing test as part of your diagnostic assessment when you suspect ASD?

	Never	Rarely (< 10% of assessments)	Occasionally (about 30% of assessments)	Sometimes (about 50% of assessments)	Frequently (about 70% of assessments)	Usually (about 90% of assessments)	Always
	❍	❍	❍	❍	❍	❍	❍

How frequently do you order or review medical investigations as part of a diagnostic assessment when you suspect ASD?

	Never	Rarely (< 10% of assessments)	Occasionally (about 30% of assessments)	Sometimes (about 50% of assessments)	Frequently (about 70% of assessments)	Usually (about 90% of assessments)	Always
	❍	❍	❍	❍	❍	❍	❍

Which of the following medical investigations are ordered/reviewed in your service when ASD is suspected? (Tick all that apply)
❍ NA
❍ Genetic screen
❍ Fragile X test
❍ Neurological examination
❍ Full physical examination
❍ Pathological tests (Please describe) _____
❍ Other (please describe) _____

How frequently do you administer assessment tools (standardised measures and diagnostic measures for ASD) to inform the diagnostic process?

	Never	Rarely (< 10% of assessments)	Occasionally (about 30% of assessments)	Sometimes (about 50% of assessments)	Frequently (about 70% of assessments)	Usually (about 90% of assessments)	Always
	❍	❍	❍	❍	❍	❍	❍

How frequently do you review the results of assessments (standardised measures and diagnostic measures for ASD) that have been administered by other clinicians?

	Never	Rarely (<10% of assessments)	Occasionally (about 30% of assessments)	Sometimes (about 50% of assessments	Frequently (about 70% of assessments)	Usually (about 90% of assessments)	Always
	❍	❍	❍	❍	❍	❍	❍

Which of the following assessment tools do you administer in as part of an assessment? (Tick all that apply)
❍ Developmental history
❍ Developmental assessment, e.g. Griffiths, Bayley
❍ Cognitive assessment, e.g. WISC, Leiter
❍ Language/communication assessment
❍ Assessment of adaptive behaviour
❍ Diagnostic measures for ASD
❍ Other psychometric assessment

Which of the following assessments might you review as part of a diagnostic assessment? (Tick all that apply)
❍ Developmental history
❍ Developmental assessment
❍ Cognitive assessment
❍ Language/communication assessment
❍ Assessment of adaptive behaviour
❍Diagnostic measures for ASD
❍Other psychometric assessment
❍ Other specialist reports, e.g. Psychologist (please describe) _____

Which of the following measures do you administer as part of an assessment when you suspect ASD? (Tick all that apply)
❍ Griffiths Mental Development Scales
❍ Bayley Scales of Infant Development
❍ Mullen Scales of Early Learning
❍ Other (please specify) _____

Which of the following measures do you review in assessments when you suspect ASD? (Tick all that apply)
❍ Griffiths Mental Development Scales
❍ Bayley Scales of Infant Development
❍ Mullen Scales of Early Learning
❍ Other (please specify) _____

Which of the following assessments of cognitive ability do you routinely administer as part of an assessment when you suspect ASD?
❍ Wechsler Preschool and Primary Scale of Intelligence (WPPSI)
❍Wechsler Intelligence Scale for Children (WISC)
❍ Wechsler Adult Intelligence Scale (WAIS)
❍ Leiter International Performance Scale
❍ Universal Nonverbal Intelligence Test (UNIT)
❍ Wechsler Nonverbal Scale of Ability (WNV)
❍ Other (please specify) _____

Which of the following assessments of cognitive ability do you review in assessments when you suspect ASD?
❍ Wechsler Preschool and Primary Scale of Intelligence (WPPSI)
❍ Wechsler Intelligence Scale for Children (WISC)
❍ Wechsler Adult Intelligence Scale (WAIS)
❍ Leiter International Performance Scale
❍ Universal Nonverbal Intelligence Test (UNIT)
❍ Wechsler Nonverbal Scale of Ability (WNV)
❍ Other (please specify) _____

❍ Which of the following communication measures do you administer as part of an assessment when you suspect ASD??
❍ Clinical Evaluation of Language Fundamentals (CELF)
❍ Comprehensive Assessment of Spoken Language (CASL)
❍ Children's Communication Checklist-2 (CCC-2)
❍ Communication Checklist-Adult (CC-A)
❍ Preschool Language Scale (PLS)
❍ Other (please specify) _____

Which of the following communication measures do you review in assessments when you suspect ASD?
❍ Clinical Evaluation of Language Fundamentals (CELF)
❍ Comprehensive Assessment of Spoken Language (CASL)
❍ Children's Communication Checklist-2 (CCC-2)
❍ Communication Checklist-Adult (CC-A)
❍ Preschool Language Scale (PLS)
❍ Other (please specify) _____

Which of the following measures of adaptive behaviour do you administer as part of an assessment when you suspect ASD?
❍ Vineland Adaptive Behaviour Scale (VABS)
❍ Adaptive Behaviour Assessment System (ABAS)
❍ Adaptive Behaviour Scale (ABS)
❍ Scales of Independent Behaviour
❍ Other (Please describe) _____

Which of the following measures of adaptive behaviour do you review in assessments when you suspect ASD?
❍ Vineland Adaptive Behaviour Scale (VABS)
❍ Adaptive Behaviour Assessment System (ABAS)
❍ Adaptive Behaviour Scale (ABS)
❍ Scales of Independent Behaviour
❍ Other (Please describe) _____

Which of the following measures of ASD characteristics do you administer as part of an assessment when you suspect ASD? (Tick all that apply)
❍ Autism Diagnostic Observation Schedule (ADOS)
❍ Autism Diagnostic Interview (ADI)
❍ Developmental, Dimensional and Diagnostic Interview (3Di)
❍ Diagnostic Interview for Social and Communication Disorders (DISCO)
❍ Childhood Autism Rating Scale (CARS)
❍ Modified Checklist for Autism in Toddlers (M-CHAT)
❍ Social Communication Questionnaire (SCQ)
❍ Autism Spectrum Screening Questionnaire (ASSQ)
❍ Australian Scale for Asperger Syndrome
❍ Autism Spectrum Rating Scale (ASRS)
❍ Childhood Autism Spectrum Test (CAST)
❍ Social Responsiveness Scale (SRS)
❍ Other (please specify) _____

Which of the following measures of ASD characteristics do you review in assessments when you suspect ASD? (Tick all that apply)
❍ Autism Diagnostic Observation Schedule (ADOS)
❍ Autism Diagnostic Interview (ADI)
❍ Developmental, Dimensional and Diagnostic Interview (3Di)
❍ Diagnostic Interview for Social and Communication Disorders (DISCO)
❍ Childhood Autism Rating Scale (CARS)
❍ Modified Checklist for Autism in Toddlers (M-CHAT)
❍ Social Communication Questionnaire (SCQ)
❍ Autism Spectrum Screening Questionnaire (ASSQ)
❍ Australian Scale for Asperger Syndrome
❍ Autism Spectrum Rating Scale (ASRS)
❍ Childhood Autism Spectrum Test (CAST)
❍ Social Responsiveness Scale (SRS)
❍ Other (please specify) _____

Which of the following psychometric measures do you administer as part of an assessment when you suspect ASD?
❍ Connors' Rating Scales
❍ Child Behaviour Checklist (CBCL)
❍ Strengths and Difficulties Questionnaire (SDQ)
❍ Behaviour Rating Inventory of Executive Functioning (BRIEF)
❍ Standardised measure of depression (please describe) _____
❍ Standardised measure of anxiety (please describe) _____
❍ Other (please specify) _____

Which of the following psychometric measures do you review in assessments when you suspect ASD?
❍ Connors' Rating Scales
❍ Child Behaviour Checklist (CBCL)
❍ Strengths and Difficulties Questionnaire (SDQ)
❍ Behaviour Rating Inventory of Executive Functioning (BRIEF)
❍ Standardised measure of depression (please describe) _____
❍ Standardised measure of anxiety (please describe) _____
❍ Other (please specify) _____

For which of the following reasons do you conduct an assessment without administering any assessment measures? (Tick all that apply)
❍ Assessment tools not available
❍ Cost of assessment tools is to high
❍ Not part of everyday practice
❍ Constraints of the family e.g. ESL, time limitations
❍ Time constraints
❍ Assessment measures have already been administered at another service
❍ Age of individual (please describe) _____
❍ Skills of the individual (please describe) _____
❍ Other (please specify) _____

For which of the following reasons do you conduct an assessment without reviewing the results of any assessment measures? (Tick all that apply)
❍ Results of assessment tools not available
❍ Not part of everyday practice
❍ Time constraints
❍ Lack of services available to conduct these assessments
❍ Other (please specify) _____

For which of the following reasons do you conduct assessments without implementing diagnostic measures for ASD? (Tick all that apply)
❍ Assessment tools not available
❍ Cost of the assessment tools is too high
❍ Not part of everyday practice
❍ Not trained in administering the assessment tool
❍ Time constraints
❍ ASD-specific assessment measures have already been administered by another service
❍ Age of the individual (Please describe) _____
❍ Skills of the individual (Please describe) _____
❍ Family constraints (Please describe) _____
❍ Other (please specify) _____
❍ Not necessary

Providing Feedback from the Assessment Process

How frequently do you offer families an appointment in which they receive feedback from the assessment process?

	Never	Rarely (< 10% of assessments)	Occasionally (about 30% of assessments)	Sometimes (about 50% of assessments)	Frequently (about 70% of assessments)	Usually (about 90% of assessments)	Always
	❍	❍	❍	❍	❍	❍	❍

If families do not attend a feedback appointment, how do you inform them of the assessment outcomes?
❍ Don't notify the family directly
❍ Mail
❍ Telephone
❍ Face-to-face
❍ Other (Please specify) _____

How long after the completion of the assessment (average number of weeks) do you typically schedule a feedback session?

How long (in minutes) is a typical appointment in which families receive feedback from the assessment process?

Of the clinicians involved in the diagnostic process, which attend the feedback appointment? (Tick all that apply)
❍ Paediatrician
❍ Psychiatrist
❍ Psychologist
❍ Speech pathologist
❍ Occupational therapist
❍ Referring clinician
❍ Other (please specify) _____

Diagnostic Report

Do you provide families with a diagnostic report following an ASD assessment?
❍ Yes
❍ No

Who is responsible for preparing the diagnostic report?
❍ Paediatrician
❍ Psychiatrist
❍ Psychologist
❍ Speech Pathologist
❍ Occupational Therapist
❍ Multidisciplinary Team
❍ Referring Clinician
❍ Each clinician prepares separate reports
❍ Other (please describe) _____

How frequently are each of the following components included in a diagnostic report?

	Never	Rarely (< 10% of reports)	Occasionally (about 30% of reports)	Sometimes (about 50% of reports)	Frequently (about 70% of reports)	Usually (about 90% of reports)	Always
Summary of assessment process	❍	❍	❍	❍	❍	❍	❍
Assessment outcomes	❍	❍	❍	❍	❍	❍	❍
Statement of the specific criteria that apply to the individual being assessed	❍	❍	❍	❍	❍	❍	❍
Statement of diagnosis	❍	❍	❍	❍	❍	❍	❍
Justification of diagnostic decision	❍	❍	❍	❍	❍	❍	❍
Description of general development	❍	❍	❍	❍	❍	❍	❍
Description of clinical history	❍	❍	❍	❍	❍	❍	❍
Results of specific assessment tools, e.g. ADOS, language, cognitive, adaptive assessments	❍	❍	❍	❍	❍	❍	❍
Recommendations	❍	❍	❍	❍	❍	❍	❍
Other (please describe)	❍	❍	❍	❍	❍	❍	❍

For which of the following reasons do you not provide a diagnostic report following an ASD assessment?

❍ Lack of time
❍ Lack of resources
❍ Cost to the family
❍ Not part of standard practice
❍ Diagnostic report written by another professional
❍ Other (please describe) _____

Cost of Diagnostic Assessments for ASD

What is the cost of an ASD assessment (per session) in your service?

What is the total cost for an ASD assessment in your service (including costs for report writing)?

Which of the following financial benefits are available to families for ASD assessment in your service?
❍ Not applicable - service is fully subsidised
❍ Medicare rebates, e.g. Helping Children with Autism (HCWA) items for private diagnosis
❍ Private health rebates
❍ Reduced fees for individuals with pension/Health Care Cards
❍ Other state-specific funding (please describe) _____
❍ Other (please describe) _____

Diagnoses Applied to Individuals Presenting for a Diagnostic Assessment

In what percentage of your assessments is each of the following clinicians responsible for making the final diagnostic decision?
_____ Paediatrician
_____ Psychiatrist
_____ Psychologist
_____ Speech Pathologist
_____ Occupational Therapist
_____ Referring Clinician
_____ Consensus decision between multidisciplinary team
_____ Other (please describe)

Overall, what percentage of your assessments result in a diagnosis on the Autism Spectrum (Autistic Disorder, Autism Spectrum Disorder, Asperger's Disorder, Pervasive Developmental Disorder-Not Otherwise Specified, Atypical Autism)?
_____

In the past 12 months, approximately what percentage of your assessments in have resulted in each of the following diagnoses? (Total must sum to 100)
_____ Autistic Disorder (Autism)
_____ Asperger's Disorder
_____ Pervasive Developmental Disorder-Not Otherwise Specified
_____ Atypical Autism
_____ Autism Spectrum Disorder
_____ Non-ASD diagnosis
_____ No diagnosis

Of the individuals you do not diagnose with ASD, approximately what percentage receive each of the following diagnoses?
_____ Rett's Disorder
_____ Global Developmental Delay
_____ Intellectual Disability
_____ Selective Mutism
_____ Language Disorder
_____ Social Communication Disorder
_____ Pragmatic Language Impairment
_____ Attention Deficit Hyperactivity Disorder
_____ Stereotypic Movement Disorder
_____ Childhood Disintegrative Disorder
_____ Attachment Disorder
_____ Schizophrenia
_____ Anxiety Disorder
_____ Personality Disorder
_____ Other (please specify)

Of the individuals you diagnose with ASD, approximately what percentage receive each of the following additional diagnoses?
_____ No additional diagnosis
_____ Attention Deficit Hyperactivity Disorder
_____ Global Developmental Delay
_____ Intellectual Disability
_____ Anxiety Disorder
_____ Mood Disorder
_____ Oppositional Defiance Disorder
_____ Language Disorder
_____ Other mental health condition (please specify)
_____ Other developmental disorder (please specify)
_____ Other communication disorder (please specify)

Resolving Diagnostic Uncertainty

Do any of your diagnostic assessments for ASD result in a 'provisional' diagnosis?
❍ Yes
❍ No

How frequently do you assign a 'provisional' ASD diagnosis?

	Never	Rarely (<10% of assessments)	Occassionally (about 30% of assessments)	Sometimes (about 50% of assessments)	Frequently (about 70% of assessments)	Usually (about 90% of assessments)	Always
	❍	❍	❍	❍	❍	❍	❍

What are the circumstances in which you would assign a 'provisional' ASD diagnosis? (Tick all that apply)
❍ When the individual is displaying 'sub threshold' ASD traits
❍ When the child is very young
❍ When the child would benefit from intervention
❍ Other (please describe) _____

Which of the following services are individuals with a 'provisional' ASD diagnosis eligible for in your state? (Tick all that apply)
❍ School-based supports, e.g. Education Assistant
❍ Respite services
❍ Disability services
❍ Individuals are only eligible for services if they have a confirmed ASD diagnosis
❍ Other (please describe) _____

If you assign a provisional ASD diagnosis, do you re-assess the individual at a later time?
❍ Yes
❍ No

How long after the original assessment (average number of weeks) do you typically re-assess the individual?

Ensuring an ASD Diagnosis
In this block of questions, you will be asked about circumstances in which you may have given an individual an ASD diagnosis, even though he/she does not meet full criteria for the disorder. In these instances, you may have judged that the potential benefits of the diagnosis, e.g. access to supports, outweighed the potential risks.

Have you ever diagnosed ASD when a person does not meet full criteria for the disorder?
❍ Yes
❍ No

How frequently do you assign ASD diagnoses when the individual does not meet full criteria for the disorder?

	Never	Rarely (< 10% of assessments)	Occassionally (about 30% of assessments)	Sometimes (about 50% of assessments)	Frequently (about 70% of assessments)	Usually (about 90% of assessments)	Always
	❍	❍	❍	❍	❍	❍	❍

Under which of the following circumstances would you diagnose ASD when the person does not meet full criteria for the disorder? (Tick all that apply)
❍ When the child was approaching the age limit for accessing early intervention funding.
❍ When I thought that the child would benefit from early intervention
❍ When there was a pressing need for the family to access support, e.g. due to family crisis or significant behavioural difficulties
❍ When there was pressure from the family to provide an ASD diagnosis
❍ So that the child could access support in the school environment
❍ So that the individual could access disability services
❍ When I thought that the individual did have ASD, but the assessment did not represent the individuals' usual presentation.
❍ So that the individual could access government funding
❍ Other (please describe) _____

Families Seeking Diagnostic Assessments for ASD

Have you had families visit your diagnostic service after having a previous assessment (from another diagnostic service) that did not result in an ASD diagnosis?
❍ Yes
❍ No

How frequently do you see families that have previously had a developmental assessment which has NOT resulted in an ASD diagnosis?

	Never	Rarely (< 10% of cases)	Occasionally (about 30% of cases)	Sometimes (about 50% of cases)	Frequently (about 70% of cases)	Usually (about 90% of cases)	Always
	❍	❍	❍	❍	❍	❍	❍

For which of the following reasons have the initial assessments not resulted in an ASD diagnosis? (Tick all that apply)
❍ Child was too young
❍ Family moved away
❍ Family stopped attending appointments
❍ The child doesn't have an ASD
❍ Complex diagnosis
❍ The child demonstrates some ASD characteristics
❍ The child has characteristics of other developmental disorders that resemble ASD
❍ The child has a syndrome that commonly co-occurs with ASD, e.g. Fragile X
❍ Other (please describe) _____

What percentage of these assessments result in an ASD diagnosis in your service?
_____

Classification System for Assigning Diagnoses
This series of questions asks about the classification system that your service employs in diagnostic assessments for ASD.

Which classification system do you currently use to assign diagnoses?
❍ ICD-10
❍ DSM-IV
❍ DSM-5
❍ Other (please specify) _____

When did you begin to assign diagnoses according to the DSM-5?
❍ Prior to May 2013
❍ May - July 2013
❍ August - October 2013
❍ November 2013 - January 2014
❍ February - April 2014
❍ May - July 2014
❍ August - October 2014

Did you complete any training in the DSM-5 prior to implementing it in your service?
❍ Yes
❍ No

What did this training involve? (Tick all that apply)
❍ Participation in training course/workshop (face-to-face)
❍ Participation in training course/workshop (online)
❍ In-house training
❍ Other (please describe) _____

Will your service transition to using the DSM-5 to assign diagnoses?
❍ Yes
❍ No
❍ Don't know

When does your service plan to transition to use the DSM-5 to assign diagnoses?
❍ November 2014 - January 2015
❍ February - April 2015
❍ May - July 2015
❍ August - October 2015
❍ November 2015 - January 2016
❍ Unsure

Will staff in your service complete any training prior to implementing the DSM-5?
❍ Yes
❍ No
❍ Unsure/Undecided

What is this training likely to involve? (Tick all that apply)
❍ Participation in a course/workshop (face-to-face)
❍ Participation in a course/workshop (online)
❍ In-house training
❍ Other (please describe) _____

Do you assign a severity rating to ASD diagnoses?
❍ Yes
❍ No

How do you make a decision about the severity of an individuals' ASD? (Tick all that apply)
❍ According to the DSM-5 specified severity levels
❍ Based on scores of standardised assessments
❍ Based on the adaptive skills of the individual
❍ Based on clinical judgement
❍ Other (please describe) _____

Diagnostic Labels
In this series of questions, you will be asked about the DSM-5 labels that may be applied to individuals with DSM-IV diagnoses of Autistic Disorder, Asperger's Disorder, or Pervasive Developmental Disorder-Not Otherwise Specified.

For individuals previously diagnosed with Autistic Disorder in your service, what percentage do you estimate would receive each of the following DSM-5 diagnoses? (Total must sum to 100).
_____ No diagnosis
_____ Autism Spectrum Disorder
_____ Social Communication Disorder
_____ Other (please specify)

For individuals previously diagnosed with Asperger's Disorder in your service, what percentage do you estimate would receive each of the following DSM-5 diagnoses (Total must sum to 100).
_____ No diagnosis

_____ Autism Spectrum Disorder
_____ Social Communication Disorder
_____ Other (please specify)

For individuals previously diagnosed with Pervasive Developmental Disorder-Not Otherwise Specified in your service, what percentage do you estimate would receive each of the following DSM-5 diagnoses? (Total must sum to 100).
_____ No diagnosis
_____ Autism Spectrum Disorder
_____ Social Communication Disorder
_____ Other (please specify)

Social Communication Disorder

Since implementing the DSM-5 in your service, how many individuals have you diagnosed with Social Communication Disorder? Please answer this question using a number, e.g. 10.

In your opinion, would children diagnosed with Social Communication Disorder in your service have been captured in a diagnostic category in the DSM-IV?
❍ Yes
❍ No

In your opinion, what percentage of the individuals you have diagnosed with Social Communication Disorder would be captured in each of the following DSM-IV diagnostic categories? (Total must sum to 100).
_____ Autistic Disorder
_____ Asperger's Disorder
_____ Pervasive Developmental Disorder-Not Otherwise Specified
_____ Expressive Language Disorder
_____ Mixed Expressive-Receptive Language Disorder
_____ Phonological Disorder
_____ Communication Disorder-Not Otherwise Specified
_____ Childhood Disintegrative Disorder
_____ Other (Please Specify)

Services and Supports Available to Families Following an ASD Diagnosis

What services are available in your state for individuals who are diagnosed with ASD? (Tick all that apply)
❍ Helping Children with Autism (HCWA) Package
❍ National Disability Insurance Scheme (NDIS)
❍ Registration with state disability body
❍ Local Area Co-Ordination
❍ State-funded intervention services, e.g. school age intervention providers, positive behaviour teams
❍ State or territory Autism Association
❍ Local community supports, e.g. swimming lessons
❍ Education Department supports, e.g., Education Assistant
❍ Respite
❍ Other (please describe) _____

How frequently do you recommend each of the following services/supports following an ASD diagnosis?

	Never	Rarely (< 10% of assessments)	Occasionally (about 30% of assessments)	Sometimes (about 50% of assessments)	Frequently (about 70% of assessments)	Usually (about 90% of assessments)	Always
Autism Advisor	❍	❍	❍	❍	❍	❍	❍
State or Territory Autism Association	❍	❍	❍	❍	❍	❍	❍
State Disability Service Organisation	❍	❍	❍	❍	❍	❍	❍
Positive Partnerships	❍	❍	❍	❍	❍	❍	❍
Raising Children Network Website	❍	❍	❍	❍	❍	❍	❍
Autism Specific Early Learning and Care Centre	❍	❍	❍	❍	❍	❍	❍
Early intervention	❍	❍	❍	❍	❍	❍	❍
Specific type of intervention, e.g. ABA, RDI, Floortime	❍	❍	❍	❍	❍	❍	❍
Speech Therapy	❍	❍	❍	❍	❍	❍	❍
Occupational Therapy	❍	❍	❍	❍	❍	❍	❍
Psychology	❍	❍	❍	❍	❍	❍	❍
Early Days Workshops	❍	❍	❍	❍	❍	❍	❍
Other (Please specify)	❍	❍	❍	❍	❍	❍	❍

Are you registered as an Autism assessor with any state or national body?
❍ Yes
❍ No

Which of the following bodies are you registered with? (Tick all that apply)
❍ Australian Psychological Society Autism and PDD identified practitioners list
❍ Western Australian Autism Diagnostician's Forum
❍ Autism South Australia
❍ Other (please specify) _____

Training in ASD Assessment and Diagnosis

For how many years have you been involved in conducting diagnostic assessments for ASD?

Have you completed any training in order to conduct diagnostic assessments for ASD?
❍ Yes
❍ No

What did this training involve? (Tick all that apply)
❍ Undergraduate training
❍ Postgraduate training
❍ Observation of experienced clinicians
❍ Participation in parts of ASD assessments under supervision
❍ Completing a full diagnostic assessment for ASD under supervision
❍ Case discussions
❍ Training in diagnostic tools (please describe) _____
❍ Training course (please describe) _____
❍ Other (please describe) _____

Would you be willing for us to contact you in the future, in the event that we seek further information relevant to this research project? Any identifying information that you provide will be stored separately from your responses to this questionnaire.
❍ Yes
❍ No

Please provide your contact information below.
Name _____
Email _____
Telephone _____

Which is your preferred mode of contact?
❍ Email
❍ Telephone

Referring Individuals for Diagnostic Assessments for ASD
This block of questions will ask about the individuals with suspected ASD who you refer for further assessment and the referral process.

In the past 12 months, how many individuals have you referred for further developmental assessment?

In the past 12 months, how many individuals have you referred for further assessment when you suspected ASD?

What is the youngest age (in years and months) that you have referred a child for an assessment when you suspected ASD?

For which of the following reasons are you likely to refer an individual for further assessment? (Tick all that apply)
❍ Parent request
❍ Parental concern about the child's overall development
❍ Parents report features consistent with ASD e.g. delayed language development, insistence on sameness
❍ Possible etiology has been identified e.g. Fragile X, tuberous sclerosis
❍ Strong family history of developmental disorder e.g. older sibling/s
❍ School or day care staff have reported concerns about the child's overall development
❍ To gain a second opinion/more information regarding an individuals' overall development
❍ Your observations of the individual indicate that there is a pattern of atypical development
❍ Individual is displaying atypical development which cannot be explained by another medical cause
❍Other (please describe) _____

Are there circumstances in which you would wait before making a referral for an Autism assessment?
❍ Yes
❍ No

Select the most likely reason that you would wait before making a referral for an Autism assessment?
❍ Child is displaying sub threshold characteristics
❍ Lack of diagnostic services to refer to
❍ To monitor the child's development
❍ Lack of confidence
❍ Lengthy wait times for developmental assessments
❍ The family is reluctant to pursue a referral for further developmental assessment
❍ Atypical development is better explained by another medical, developmental, or sensory (e.g. hearing loss) cause
❍ Age of the individual (please describe) _____
❍ Other (please describe) _____

Of the clients that you refer for further assessment, approximately what percentage come from each of the following age groups? (Total must equal 100)
_____ 0 - 12 months
_____ 1 - 2 years
_____ 2 - 3 years
_____ 3 - 5 years
_____ 5 - 8 years
_____ 8 - 12 years
_____ 12 - 18 years
_____ 18 - 25 years
_____ 25 - 50 years
_____ 50 - 65 years
_____ More than 65 years

In the past 12 months, how many families have visited your practice seeking a referral for an assessment after previous attempts to gain referrals have been unsuccessful?

For which of the following reasons have families been unable to attain a referral for an assessment prior to visiting your practice (Tick all that apply)
❍ Not Applicable
❍ Child too young
❍ Child not demonstrating atypical development in any area
❍ Lack of services to refer to
❍ The family had previously been reluctant to pursue further assessment
❍ Other (please describe) _____

Of the families who have visited your practice after being unable to attain a referral, how many have you referred for further assessment?

Do you routinely order a hearing test prior to referring an individual for further assessment?
❍ Yes
❍ No

Do you routinely order any medical investigations prior to referring an individual for further assessment?
❍ Yes
❍ No

Which of the following medical investigations do you typically order prior to referring an individual for further assessment? (Tick all that apply)
❍ Full physical examination
❍ Vision assessment
❍ Pathological investigations (please describe) _____
❍ Genetic investigations (please describe) _____
❍ Other (please describe) _____

Do you routinely conduct any developmental screening prior to referring an individual for further assessment?
❍ Yes
❍ No

Which of the following screening tools do you typically use before referring an individual with suspected ASD for further assessment? (Tick all that apply)
❍ Childhood Autism Rating Scale (CARS)
❍ Modified Checklist for Autism in Toddlers (M-CHAT)
❍ Social Communication Questionnaire (SCQ)
❍ Autism Spectrum Screening Questionnaire (ASSQ)
❍ Children's Communication Checklist (CCC-2)
❍ Childhood Autism Spectrum Test (CAST)
❍ Autism Spectrum Rating Scale (ASRS)
❍ Social Responsiveness Scale (SRS)
❍ Australian Scale for Asperger Syndrome
❍ Preschool Language Scale
❍ Parents Evaluation of Developmental Status (PEDS)
❍ Ages and Stages Questionnaire (ASQ)
❍ Infant-Toddler Checklist
❍ Receptive-Expressive Emergent Language Test (REELS-3)
❍ Developmental Behaviour Checklist (DBC)
❍ Child Development Inventory
❍ Developmental Profile-3
❍ Developmental Screener (please describe) _____
❍ Other (please specify) _____

Location of Service
These questions will ask about the location of your primary practice and the regions of Australia for which your service is based

What is the postcode of your primary practice setting (i.e. where you spend more than 50% of your working time)?

In which area/s of Australia do you practice? (Tick all that apply)
❍ Metropolitan
❍ Regional, rural or remote
❍ Other (please describe) _____

What percentage of the individuals that attend your practice come from each of the following areas of Australia? (See map above for definitions)
_____ Major city
_____ Inner regional
_____ Outer regional
_____ Remote
_____ Very remote

Referrals for Assessment in Regional, Rural, or Remote Areas of Australia
This series of questions ask specifically about referrals for families who live in regional, rural and remote areas of Australia. Please consider only these families when responding to this set of questions.

What is the approximate radius (in km) of the region for which you conduct a referral service?
❍ 50km
❍ 50km- 100km
❍ 100km - 150km
❍ 150km - 200km
❍ 200km - 250km
❍ 250km - 300km
❍ 300km -350km
❍ 350km - 400km
❍ 400km - 450km
❍ 450km - 500km
❍ More than 500km

What percentage of the families that you refer travel for each of the following durations to access your service?
_____ Less than one hour
_____ 1 - 2 Hours
_____ 2 - 3 Hours
_____ 4 - 5 Hours
_____ More than 5 hours

What percentage of the individuals that you refer come from each of the following age bands? (Total must sum to 100)
_____ 0 - 12 months
_____ 1 - 2 years
_____ 2 - 3 years
_____ 3 - 4 years
_____ 4 - 5 years
_____ 5 - 8 years
_____ 8 - 12 years
_____ 12 - 18 years
_____ 18 - 25 years
_____ 26 - 60 years
_____ More than 60 years

Are there circumstances in which you would defer making a referral for further assessment?
❍ Yes
❍ No

Select the most likely reason that you would defer a referral for further assessment?
❍ Child is displaying sub threshold characteristics
❍ Lack of diagnostic services to refer to
❍ To monitor the child's development
❍ Lack of confidence
❍ Lengthy wait times for developmental assessments
❍ The family is reluctant to pursue a referral for further developmental assessment
❍ Atypical development is better explained by another medical, developmental, or sensory (e.g. hearing loss) cause
❍ Age of the individual (please describe) _____
❍ Other (please describe) _____

What type of financial assistance is available to families that travel long distances to access an assessment? (Tick all that apply)
❍ Patient Assisted Travel Scheme
❍ Unsure
❍ Other (please describe) _____
❍ Not applicable (please specify) _____