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Missed opportunities: An investigation of pathways to autism diagnosis in Australia

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ABSTRACT

Background: Reliable diagnoses of autism can be made as early as two years of age. Many children in Australia are diagnosed with autism at a later age. Delayed diagnosis can lead to missed opportunities for early intervention. This study aims to investigate the factors associated with age of diagnosis in Australia and to examine where delays are occurring in the diagnostic pathway.
Method: Family and child characteristics, age of first concern, and outcomes of previous professional consultations were collected and analysed for 215 children undergoing assessment for autism in Sydney, Australia.
Results: The average age of diagnosis was 5 years. Children with more severe autism, and those with no co-morbid diagnosis were diagnosed at a younger age. Average age of first concern was 23 months, and parents consulted professionals, on average, just over 8 months later. Seventy percent of the children were not identified as having possible autism at this initial consultation. The average gap between first consultation and diagnosis of autism was 2 years, 4 months.
Conclusions: This study provided further evidence of delayed diagnosis of children in Australia. Those with level 2 or 3 autism, no co-morbid diagnosis and earlier parental first concerns were diagnosed earlier. In general, parents have concerns and take action in a timely manner. Delays in the diagnostic pathway were apparent from the first professional consultation where autism was often not identified. This could be addressed by training professionals about early indicators, milder forms of autism, and differential diagnosis.

1. Introduction

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder characterised by deficits in social communication and social interaction, as well as the presence of restricted and repetitive interests, behaviours or activities (American Psychiatric Association, 2013). The American Centres for Disease Control and Prevention (2014) report that prevalence rates of ASD are as high as 1 in 59 children (Baio et al., 2018). Estimated prevalence rates in Australia based on census figures have increased by 42% since 2012 (Australian Bureau of Statistics, 2015). The reason for the increase in ASD has been a topic of debate and may be due to better detection, improved awareness, diagnosis of children with milder symptoms, and changes in diagnostic practices, rather than a surge in the number of children with ASD (Hansen, Schendel, & Parner, 2015; Liu, King, & Bearman, 2010; Whitehouse et al., 2017).

There is increasing awareness of the importance of early intervention for children with ASD (Fein et al., 2013). Children who

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receive early intervention demonstrate improved cognitive, developmental and adaptive functioning, enhanced language and social skills as well as a decrease in symptom severity, cognitive impairment, and maladaptive behaviours as compared to children who are treated later (Eldevik et al., 2009; Magiati, Tay, & Howlin, 2014; Oono, Honey, & McConachie, 2013; Vismara & Rogers, 2010). There is also some evidence to suggest that children who receive intervention before the age of three have better outcomes than children who receive intervention after three years of age (Goin & Myers, 2004; Landa, Holman, & Garrett-Mayer, 2007; Sheinkopf & Siegel, 2004; Zwaigenbaum et al., 2015). In a recent Australian study, children diagnosed before age 3 demonstrated better verbal skills and higher scores on cognitive testing than children diagnosed after 3 years of age (Clark, Vinen, Barbaro, & Dissanayake, 2018). Clearly, it is important for a child on the autism spectrum to receive an early diagnosis, ideally before the age of three, so that they can receive appropriate early intervention and achieve optimal outcomes.

1.1. Pathways to diagnosis

There are a number of steps that typically occur on the pathway to diagnosis for children with autism. Firstly, parents become aware of developmental differences in their children, either from their own observations or following concerns raised by childcare, health, or education professionals. This often occurs as early as 12–18 months of age (Preeti, Srinath, Seshadri, Girimaji, & Commu, 2017; Wimpory, Hobson, Williams, & Nash, 2000; Zuckerman, Lindly, & Sinche, 2015). The next step in the typical diagnostic pathway is that parents or carers will consult with a professional in relation to their concerns, however in some cases a considerable period of time may elapse before this occurs as parents may adopt a “wait and see” approach (Preeti et al., 2017). The final step is that the professional who is consulted must then recognise the signs of autism and either confirm the diagnosis or refer to a specialist service. There can be delays in receiving a diagnosis at this stage as some professionals take a passive approach by providing inaccurate reassurance (Ryan & Salisbury, 2012), opting to wait until the child is older to make a diagnostic decision (Rutter, 2006; Ward, Sullivan, & Gilmore, 2016), or providing an inaccurate or alternative diagnosis (Mazurek et al., 2014). Even when professionals do take an active approach such as referring the child for an assessment, parents can experience long wait times for expert assessment services, particularly in regional areas (Wiggins, Baio, & Rice, 2006). Thus, in order for a child to receive a diagnosis, parents or carers must be aware of developmental differences and take action by consulting a professional, and the professional must recognise the signs of autism and either make the diagnosis or refer to someone who can.

1.2. Factors associated with age of diagnosis

It is possible for a reliable diagnosis of ASD to be made by 2 years of age (Lord et al., 2006; Pinto-Martin, Dunkle, Earls, Fliedner, & Landes, 2005; Steiner, Goldsmith, Snow, & Chawarska, 2012). However, a review of the literature spanning twenty years found that the average age of diagnosis across 42 studies was between 3 years, 2 months and 10 years (Daniels & Mandell, 2013). Factors consistently shown to be associated with early diagnosis included greater symptom severity, higher socioeconomic status, and greater parental concern. Some studies found an effect for birth order and location, with firstborn children and those living in regional and rural areas diagnosed later (Bent, Dissanayake, & Barbaro, 2015; Coo, Ouellette-Kuntz, Lam, & Yu, 2012; Fountain, King, & Bearman, 2011; Frenette et al., 2011; Ryan & Salisbury, 2012). A number of studies have found that girls are diagnosed, on average, later than boys (Halladay et al., 2015; Rutherford et al., 2016). Children with co-morbid diagnoses such as ADHD, developmental delays/intellectual disability, and behavioural disorders may also receive later diagnoses due to overlapping symptoms and difficulties with differential diagnosis (Mazurek et al., 2014; Zuckerman et al., 2015). Thus, a number of child, family and community characteristics have been shown to be associated with age of diagnosis; however, the results across time and context have been variable.

Age of diagnosis can be associated with location specific characteristics such as educational and assessment practices, service access, and funding policies (Mandell et al., 2010; Rosenberg, Landa, Law, Stuart, & Law, 2011; Shattuck et al., 2009). By way of background, Australia has had a national program of individualised funding for children with autism since 2008 (Helping Children with Autism Program) which has more recently expanded to people with disability of any age (National Disability Insurance Program). Developmental screening practices vary across jurisdictions but are typically conducted by general practitioners or maternal health care nurses. In New South Wales (NSW), developmental screening does not routinely include autism screening. There is considerable variability in diagnostic processes for autism in Australia both in terms of professionals involved in conducting assessments (e.g. single clinician versus multi-disciplinary team, private practice versus funded assessment service) and diagnostic practices (use of autism specific assessment tools, inclusion of developmental, language and cognitive assessment tools) (Ward et al., 2016).

1.3. Age of diagnosis in Australia

A recent study aimed at investigating the frequency and age of diagnosis in Australia found the average age of diagnosis was 4 years, 1 month, the most common age was 5 years, 11 months, and approximately 26% of children of Australian children with ASD are not diagnosed before their sixth birthday (Bent et al., 2015). Thus, there is a gap between the age that a child can be reliably diagnosed and the age at which children do receive a diagnosis of ASD in Australia. However, this study was based on data collected from an Australian government funding program limited to children aged 6 and under (Helping Children with Autism Program). These estimates may therefore be an underestimation of the average age of diagnosis across all age ranges in Australia (Bent et al., 2015).

In order to develop targeted education strategies and policy aimed at facilitating early diagnosis in a particular community, it is

Table 1
Participant characteristics.

Demographic characteristics (n = 215)		
Age (mean)	5.15 years	SD = 2.41
Sibling with ASD	26	12%
First born	122	56.7%
Gender		
Male	167	77.21%
Female	48	22.3%
Location		
Urban	110	51.1%
Rural	105	48.9%
Social severity level (n = 208)		
Level 1	97	45.1%
Level 2	90	41.9%
Level 3	21	9.8%
RRB severity level (n = 208)		
Level 1	91	42.3%
Level 2	108	50.2%
Level 3	9	4.2%

important to understand what factors are associated with age of diagnosis in that community and where any delays are occurring in the pathway to diagnosis for children. Therefore this study aims to:

1. explore the relationship between age of diagnosis and a number of possible related factors, i.e. age of first concern, gender, autism severity, presence of co-morbid diagnoses, birth order, sibling previously diagnosed with autism, and urban versus rural location, for a sample of children referred to a tertiary referral clinic in New South Wales, Australia.
2. investigate where the delays may be occurring in the diagnostic pathway by examining how the related factors outlined above may be associated with the time between parent's recall of first concern and consultation with a professional and the time between first consultation and diagnosis of autism.

2. Method

2.1. Participants

Participant characteristics are listed in Table 1. The sample consisted of 215 children diagnosed with autism at a tertiary-level autism specific assessment service located in Sydney, Australia between January 2016 and July 2017. Participants ranged in age from one year, four months (16 months) to eleven years, 11 months (143 months) (M = 5.15 years, SD = 28.9 months). Males comprised 77.7% of the sample (n = 167) and 22.3% were female (n = 48). Just over half of the sample (51.1%) resided in an urban location (n = 110) and 48.9% lived in rural locations (n = 105). Rural was defined as locations in the Australian state of New South Wales that are outside the Greater Sydney Metropolitan area. Twenty six participants (12%) had a sibling who had previously been diagnosed with autism spectrum disorder and 56.7% (n = 122) were the oldest child in their family. Severity levels were applied to 208 children according to DSM5 descriptions. There were 7 children who, due to their young age (< 21 months), were recommended for further assessment at a later date for assignment of severity levels. With regards to social severity levels, 45.1% of the participants were rated as Level 1 (n = 97), 41.9% were rated as Level 2 (n = 90), and 9.8% were rated as Level 3 (n = 21). For restricted and repetitive behavior (RRB) severity levels, 42.3% were rated as Level 1 (n = 91), 50.2% were rated as Level 2 (n = 108), and 4.2% were rated as Level 3 (n = 9). Children rated as Level 2 and Level 3 severity ratings were grouped together for further analysis.

2.2. Measures

Child and family demographic information was collected via parent report forms completed as part of the intake procedure for the assessment service. Demographic information included child's date of birth, address, and gender. Parents also provided all background reports from medical and allied health professionals outlining any prior diagnoses.

The Autism Diagnostic Observation Schedule – Second Edition (ADOS 2) (Lord, Rutter, DiLavore, & Risi, 2002) is a semi-structured assessment tool that measures communication ability, social interaction, and play or imaginative skills. The ADOS 2 consists of standardised activities that allow the clinician to observe behaviors that have been identified as important in the diagnosis of autism spectrum disorders at different developmental levels and chronological ages. The ADOS 2 has five modules. The clinician selects the module that is most appropriate for the particular child or adult based on their chronological age and expressive language level. Administration of the ADOS 2 takes approximately 45 min. Notes are taken during the administration of the ADOS 2 and the clinician assigns ratings at the completion of the assessment. These ratings assist in the formulation of diagnosis through the use of the diagnostic algorithm provided for each module.

The Autism Diagnostic Interview-Revised (ADI-R) (Rutter, Le Couteur, & Lord, 2003) is a standardised semi-structured interview that is administered to parents/caregivers regarding the developmental history and current behavior of the individual being assessed. The ADI-R consists of 93 items and focuses on three functional domains (language and communication, reciprocal social interaction, and RRBs). The administration time for each interview is approximately two hours. The ADI-R produces an algorithm that assists in determining whether or not an individual meets criteria for a diagnosis of ASD. All assessments outlined above have high reliability and validity, with descriptions of their psychometric properties outlined in the respective manuals.

To obtain information regarding the pathway to diagnosis, parents were asked two additional questions during the ADI-R administration:

- How old was your child when you first consulted a health professional regarding your child's development?
- What was the outcome of this consultation? Responses were coded as follows: No identification of possible ASD (e.g. reassurance all is well, alternative diagnosis, wait and see) or identification of possible ASD (e.g. referral for autism assessment or diagnosis applied).

2.3. Procedure

The study protocol was approved by Autism Spectrum Australia's Research Approvals Committee. Informed consent was obtained from parents prior to participation in the study. The research was conducted during a day-long assessment for possible autism spectrum disorder.

Prior to the assessment date, parents completed intake forms with demographic information and provided all previous diagnostic reports and a referral letter.

The assessment consisted of informal observations, ADOS 2, and ADI-R. The relevant ADOS 2 module was administered and an ADI-R was completed with parents/carers. Assessments were conducted by psychologists and clinical psychologists working at a specialised autism assessment service. All clinicians have completed formal training in the administration of the ADOS 2 and ADI-R, and administer them as routine components of all assessments. Diagnosis was made and severity levels applied according to DSM-5 criteria. The diagnostic decision was based on clinical judgment, which was informed by scores from the ADOS 2 and ADI-R, along with information gathered from background reports and teachers or other professionals. All children diagnosed with ASD were included in the study.

2.4. Data analysis

Preliminary analyses included descriptive statistics. The relationship between age of first concern and age of diagnosis was investigated using Spearman Rank Order Correlation. Mann–Whitney *U* tests were used to analyse the differences in location (urban/rural), gender, sibling with ASD (yes/no), and first born (yes/no), co-morbid diagnosis (yes/no), autism severity social (level1/level 2 and 3), and autism severity RRBs (level 1/level 2 and 3) on the following dependent variables:

- Age of diagnosis
- “parent gap” – defined as the time, in months, between parents’ first concerns and their first consultation with a health professional regarding their concerns
- “professional gap” – defined as the time, in months, between the first consultation with a health professional and age of diagnosis.

Regression analysis was also conducted to further investigate the relationship between the variables of interest and age of diagnosis.

3. Results

3.1. Age of diagnosis

The average age of diagnosis in this sample was 5 years (60.67 months) ($M = 5.05$ years, range = 16 months to 11 years, 6 months, $SD = 27.99$ months). In this sample, only 6% of children ($n = 13$) were diagnosed with autism spectrum disorder by 2 years of age. Thirty one percent ($n = 67$) were diagnosed after 6 years of age, which is after the compulsory school entry age in NSW (Table 2).

The average age when parents first became concerned about their child's development was 1 year, 11 months (23.75 months) ($M = 1.97$ years, $SD = 14.35$ months). The relationship between age of first concern and age of diagnosis was investigated using Spearman rank order correlation. There was a strong, positive correlation between the two variables, $r = .418$, $n = 213$, $p = < 0.001$, with older age of first concerns associated with older age of diagnosis.

Mann–Whitney *U* tests were conducted to examine the relationship between the variables of interest (location, gender, sibling with ASD, birth order, co-morbid diagnosis, social severity level and RRB severity level) and the age of diagnosis (Table 3). There was no significant difference in this sample in the age of diagnosis for those living in rural locations as opposed to those living in urban locations ($U = 5124$, $z = -1.322$, $p = 0.186$). There was also no significant difference in the age of diagnosis depending on whether

Table 2
Frequency of diagnoses and mean of age of first concern, parent gap and professional gap, by age.

Age of diagnosis	No. of children diagnosed (%)	Age of first concern	Parent gap (months)	Professional gap (months)
< 24 months	13 (6%)	15.69	1.08	5.85
25–36 months	35 (16.3%)	15.68	4.51	11.39
37–48 months	42 (19.5%)	19.48	6.02	17
49–60 months	33 (15.3%)	21.75	10.41	21.57
61–72 months	25 (11.7%)	26.2	7.56	32.52
73–84 months	21 (9.8%)	32.95	3.85	41.84
85–96 months	19 (8.8%)	29.47	14	47
97–108 months	11 (5.1%)	33.82	27.09	40.09
109–120 months	10 (4.7%)	29.4	6	78.3
121–132 months	4 (1.9%)	46.5	15	62
133–144 months	2 (0.9%)	24	1	110.5

Table 3
z scores and significance of variables of interest for age of diagnosis, parent gap and professional gap.

Participant characteristic	Age of diagnosis (z scores)	Parent gap (z scores)	Professional gap (z scores)
Gender	−1.875	−1.434	−0.015
Rural/urban	−1.322	−2.507*	−0.302
Birth order	−0.468	−0.916	−0.581
Sibling with ASD	−0.293	−0.946	−0.179
Social severity level	−7.543*	−1.593	−4.083*
RRB severity level	−2.282*	−1.222	−1.348
Co-existing diagnosis	−3.552*	−0.629	−3.358*

* Significant at 0.05.

the child was a firstborn ($U = 5402$, $z = -0.468$, $p = 0.640$), or whether they had a sibling who had been diagnosed with ASD ($U = 2194$, $z = -0.293$, $p = 0.770$).

Although not reaching significance ($U = 3296$, $z = -1.875$, $p = 0.061$) there was a trend towards younger age of diagnosis for males. The average age of diagnosis for males was 4 years, 11 months (59.10 months), while the average age of diagnosis for females was 6 years, 5 months (77.13 months).

The severity of ASD social symptoms ($U = 2117$, $z = -7.543$, $p < 0.001$) and ASD RRB symptoms ($U = 4341$, $z = -2.282$, $p = 0.022$) were both found to significantly impact the age of diagnosis. On average, children who received a social severity rating of Level 1 were diagnosed at the age of 6 years, 4 months (76.63 months), which was significantly later than children who received a social severity rating of Level 2 or Level 3 who were diagnosed at an average age of 4 years, 1 month (59.14 months). As such, children with more severe social symptoms were diagnosed an average of 3 years, 3 months earlier than those with less severe social symptoms. Similarly, children who received a RRB severity rating of Level 1 were, on average, diagnosed at the age of 5 years, 6 months (66.05 months), which was significantly later than children with an RRB severity rating of Level 2 or Level 3, who were diagnosed at an average age of 4 years, 10 months (58.77 months). Children with more severe RRB symptoms were diagnosed an average of 8 months earlier than those with less severe RRB symptoms.

The relationship between the presence of any co-morbid condition and age of diagnosis was also examined. On average, children with any co-morbid condition were diagnosed with autism significantly later than those without any co-morbidity ($U = 4140$, $z = -3.552$, $p = < 0.001$). The mean age of diagnosis for those with a co-morbid condition was 5 years, 7 months (67.5 months), whereas the mean age of diagnosis for those without any co-morbidity was 4 years, 3 months (52.9 months). Therefore, children without any co-morbidity were diagnosed, on average, 15 months earlier than those with a co-morbid condition.

To further investigate the relationship between the variables of interest and age of diagnosis, a linear multiple regression was conducted to assess the ability of age of first concern, gender, location, birth order, social severity, RRB severity and presence of co-morbid diagnosis to predict age of diagnosis (in months). Preliminary analyses were conducted to ensure no violation of the assumptions of normality, linearity, multicollinearity and homoscedasticity. The total variance explained by the model was 41.1%, $F(8, 184) = 16.067$, $p < 0.001$. In the model, three variables were statistically significant with social severity recording the highest beta value (beta = −.424, $p < 0.001$) followed by age of first concern (beta = .273, $p < 0.001$) and presence of co-morbid condition (beta = .218, $p < 0.001$).

3.2. Time between parent concerns and consultation with a health professional (Parent gap)

On average, parents first consulted a health professional about their concerns when their child was aged 2 years, 8 months (32.12 months). The average "parent gap" was 8 months ($SD = 12.02$ months).

Mann–Whitney U tests were conducted to examine the relationship between the variables of interest and the "parent gap" (Table 3). There was no significant difference in the length of "parent gap" based on birth order ($U = 5041$, $z = -0.916$, $p = 0.360$), gender ($U = 3287$, $z = -1.434$, $p = 0.152$), having a sibling with ASD ($U = 1986$, $z = -0.946$, $p = 0.344$), severity of social symptoms ($U = 4522$, $z = -1.593$, $p = 0.111$) or RRBs ($U = 4862$, $z = 0.661$, $p = 0.508$), or presence of a co-morbid condition ($U = 5274$, $z = -0.629$, $p = 0.53$). There was an effect found for urban versus rural location ($U = 4444$, $z = -2.507$, $p = 0.012$) with the gap between parent first concern and first consult with a professional being, on average, 5 months longer for children living in rural areas ($M = 5$ months for urban areas and $M = 10$ months for rural areas).

3.3. Time between consultation with a health professional and diagnosis (Professional gap)

As outlined above, on average parents first consulted a health professional about their concerns when their child was aged 2 years, 8 months. Only 27.2% of children ($n = 56$) were either diagnosed with autism or referred for further ASD specific assessment at the first consultation. For 69.8% of children ($n = 150$), autism was not identified as a possible diagnosis at this first consultation. For 9 cases, parents could not clearly recall the outcome of the initial consultation and these cases were treated as missing data. The average "professional gap" (between first consultation with a professional and diagnosis of autism) was 2 years, 4 months (28.88 months) ($SD = 24$ months).

Mann–Whitney U tests were conducted to examine the difference between the variables of interest and "professional gap" (Table 3). There was no significant difference in "professional gap" for those living in urban locations as opposed to regional locations ($U = 5226$, $z = -0.302$, $p = 0.763$). Similarly, there was no significant difference in "professional gap" depending on whether the child was a firstborn ($U = 5003$, $z = -0.581$, $p = 0.561$), whether they had a sibling who had been diagnosed with ASD ($U = 1994.5$, $z = -0.179$, $p = 0.858$), whether they were male or female ($U = 3720$, $z = -0.015$, $p = 0.988$) or based on severity of RRBs ($U = 4472$, $z = -1.348$, $p = 0.178$).

In this sample, the severity of ASD social symptoms was found to have an impact on "professional gap" ($U = 3394.5$, $z = -4.083$, $p < 0001$). On average, children who received an ASD social severity rating of Level 1 had a "professional gap" of 3 years, 1 months (37.87 months, $SD = 28$ months). This was significantly longer than for children who received an ASD social severity rating of Level 2 or Level 3, who had a "professional gap" of 1 years, 10 months (22.24 months, $SD = 24.71$ months) on average. Results indicate that children with more severe ASD social symptoms had an average "professional gap" that was 1 year, 8 months shorter than children with more mild ASD social symptoms.

The relationship between the presence of any co-morbid condition and "professional gap" was also analysed. On average, the "professional gap" for children with any co-morbid condition was significantly longer than those without any co-morbidity ($U = 3940$, $z = -3.358$, $p = 0.001$). The mean "professional gap" for those with a co-morbid condition was 2 years, 10 months (34.72 months), whereas the mean "professional gap" for those without any co-morbidity was 1 year, 10 months (22.46 months). Therefore, children without any co-morbidity were diagnosed, on average, one year earlier than those with a co-morbid condition.

4. Discussion

In this sample of 215 children referred to an autism specific assessment centre in Sydney, New South Wales, the average age of diagnosis was 5 years. This is higher than the average age of diagnosis of 4 years, 1 month found in a previous Australian study (Bent et al., 2015), however their sample was limited to children aged 6 and under. Nevertheless, this study with a broader age sample provides additional evidence of delays in the diagnosis of autism in Australia. Although it is possible to make reliable diagnoses in some children from around 2 years of age (Lord et al., 2006; Pinto-Martin et al., 2005; Steiner et al., 2012), only 18% of this sample received a diagnosis prior to their third birthday. Autism symptoms can be sub-threshold in the very early childhood period and this would account for delays in formal diagnosis in some cases. However, only 57% of this sample were diagnosed by 5 years, an age at which most children with autism would be exhibiting significant social impairment and restricted and repetitive behaviours (Rutter et al., 2003). Even more concerning, taking into account the importance of early intervention, was the fact that 31% of children had reached school entry age prior to being diagnosed with autism.

Not surprisingly, age of diagnosis was strongly correlated with age of first concern, highlighting the importance of parental awareness of normal developmental milestones. Age of diagnosis was not impacted by other family factors such as having a sibling with ASD, birth order, or rural/regional location. Findings in relation to having a sibling with ASD and the effect of birth order have yielded mixed results in previous studies (Coo et al., 2012; Fountain et al., 2011; Frenette et al., 2011; Ryan & Salisbury, 2012). However, delays in diagnosis for children living in regional areas has been a reasonably consistent finding and was found to be the case in a recent Australian study (Bent et al., 2015). Many of the children referred for assessment from regional areas in this sample were referred by paediatricians and early intervention services practicing in regional areas that had been targeted in a ten-year funded program delivered by the assessment service. This program was aimed at increasing early identification skills in regional service providers and developing referral networks. It is possible that this training and established referral pathway removed some of the barriers that regional families face more broadly in Australia, and provides an important insight into one way that delayed diagnosis in regional areas can be addressed.

In this study, there was no gender differences for age of diagnosis. This is not consistent with previous research (Lai et al., 2015; Rutherford et al., 2016) and may reflect the increasing awareness of the subtle variation in the presentation of girls. Other child characteristics (autism severity, and presence of co-morbid diagnosis) were related to the average age of diagnosis and this is in line with earlier studies (Mazurek et al., 2014; Zuckerman et al., 2015). Children with milder forms of autism and those with co-morbid diagnoses were diagnosed later, suggesting higher rates of missed diagnosis or misdiagnosis for these children. Severity of social symptoms was most predictive of age of diagnosis indicating that further training for medical and allied health professionals in how autism may present in higher functioning individuals, particularly in relation to subtle social impairment, may facilitate earlier diagnosis. Similarly, training in differential diagnosis of autism and common co-occurring conditions may also be beneficial.

This study also attempted to gain a better understanding of how children progress through the typical pathway to diagnosis by asking parents to recall their early concerns and initial consultations with health professionals. No relationship was found between any of the variables of interest and the "parent gap" except for location, with parents living in rural areas reporting a longer gap. This difference may reflect longer wait times for appointments in rural areas compared to urban areas, rather than delays on the parent's part in relation to their concerns. Nevertheless, overall, in this sample, parents were noticing their child's differences at a reasonably young age (around age 2 on average) and consulting health professionals in a timely fashion (around 8 months later).

In contrast, delays in the diagnostic pathway were evident in this study from the point of first consultation with a professional. Only just over one quarter (27%) of the children diagnosed with autism were identified as having possible autism at the first professional consultation and/or referred on for further assessment for autism. The majority of parents (approximately 70%) reported that they were either re-assured that there were no concerns, advised to take a "wait and see" approach, or their child was diagnosed with a condition other than autism. The average "professional gap" was over 2 years, 4 months with significantly longer gaps for children with milder social symptoms and co-morbid conditions. These findings are consistent with a recent survey of Australian diagnosticians, which found that many practitioners lack confidence in identifying autism in children under 3 and have a tendency to adopt a "watch and wait" strategy in the case of diagnostic uncertainty (Ward et al., 2016).

While the sample was small and consisted of children referred to a private tertiary referral autism assessment service, the findings in relation to age of diagnosis are very similar to a recent Australia-wide survey based on children 6 and under (Bent et al., 2015). Therefore, this study provides further evidence of a gap between the age at which a diagnosis of autism can be reliably made and the average age of diagnosis in Australia. This study also sheds light on where delays may be occurring in the diagnostic pathway based on parent report. Future research using a prospective study design could provide further information about a child's progress through the diagnostic pathway in Australia.

5. Implications

Based on the findings, one way of facilitating early diagnosis in Australia would be to ensure that parents are provided with easily accessible information on developmental milestones and early signs of autism. There should also be a focus on providing training to medical and health professionals in relation to early indicators, milder forms of autism, and differential diagnosis approaches for medical and allied health professionals who see children with developmental problems. These same professionals could be encouraged to refer on to specialist assessment services rather than adopting a "wait and see" approach in the face of diagnostic uncertainty.

References

American Psychiatric Association (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: American Psychiatric Publishing.

Australian Bureau of Statistics. (2015). *Autism in Australia.* Retrieved from http://www.abs.gov.au/.

Baio, J., Wiggins, L., Christensen, D. L., Maenner, M. J., Daniels, J., Warren, Z., et al. (2018). Prevalence of autism spectrum disorder among children aged 8 years — Autism and developmental disabilities monitoring network, 11 sites, United States, 2014. *Morbidity and Mortality Weekly Report Surveillance Summaries, 67*(SS-6), 1–23. https://doi.org/10.15585/mmwr.ss6706a1.

Bent, C. A., Dissanayake, C., & Barbaro, J. (2015). Mapping the diagnosis of autism spectrum disorders in children aged under 7 years in Australia, 2010–2015. *The Medical Journal of Australia, 202*, 317–320. https://doi.org/10.5694/mja14.00328.

Clark, M., Vinen, Z., Barbaro, J., & Dissanayake, C. (2018). School age outcomes of children diagnosed early and later with autism spectrum disorder. *Journal of Autism and Developmental Disorder, 48*, 92–102. https://doi.org/10.1007/s10803-017-3279-x.

Coo, H., Ouellette-Kuntz, H., Lam, M., & Yu, C. T. (2012). Correlates of age at diagnosis of autism spectrum disorders in six Canadian regions. *Chronic Diseases and Injuries in Canada, 32*(2), 90–100.

Daniels, A. M., & Mandell, D. S. (2013). Explaining differences in age at autism spectrum disorder diagnosis: A critical review. *Autism, 18*, 583–597. https://doi.org/10.1177/1362361313480277.

Eldevik, S., Hastings, R. P., Hughes, J. C., Jahr, E., Eikeseth, S., & Cross, S. (2009). Meta-analysis of early intensive behavioural intervention for children with autism. *Journal of Clinical Child and Adolescent Psychology, 38*, 439–450. https://doi.org/10.1080/15374410902851739.

Fein, D., Barton, M., Eigsti, I. M., Kelley, E., Naigles, L., Schultz, R. T., & Troyb, E. (2013). Optimal outcome in individuals with a history of autism. *Journal of Child Psychology and Psychiatry, 54*(2), 195–205. https://doi.org/10.1111/jcpp.12037.

Fountain, C., King, M. D., & Bearman, P. S. (2011). Age of diagnosis for autism: Individual and community factors across 10 birth cohorts. *Journal of Epidemiology & Community Health, 65*(6), 503–510. https://doi.org/10.1136/jech.2009.104588.

Frenette, P., Dodds, L., MacPherson, K., Flowerdale, G., Hennen, B., & Bryson, S. (2011). Factors affecting the age at diagnosis of autism spectrum disorders in Nova Scotia, Canada. *Autism, 17*(2), 184–195. https://doi.org/10.1177/1362361311413399.

Goin, R. P., & Myers, B. J. (2004). Characteristics of infantile autism: Moving toward earlier detection. *Focus on Autism and Other Developmental Disabilities, 19*, 5–12. https://doi.org/10.1177/10883576040190010201.

Halladay, A. K., Bishop, S., Constantino, J. N., Daniels, A. M., Koenig, K., Palmer, K., xxx, & Taylor, J. L. (2015). Sex and gender differences in autism spectrum disorder: Summarizing evidence gaps and identifying emerging areas of priority. *Molecular Autism, 6*(1), 36. https://doi.org/10.1186/s13229-015-0019-y.

Hansen, S. N., Schendel, D. E., & Parner, E. T. (2015). Explaining the increase in the prevalence of Autism Spectrum Disorders: The proportion attributable to changes in reporting practices. *JAMA Pediatrics, 169*, 56–62. https://doi.org/10.1001/jamapediatrics.2014.1893.

Landa, R. J., Holman, K. C., & Garrett-Mayer, E. (2007). Social and communication development in toddlers with early and later diagnosis of autism spectrum disorders. *Archives of General Psychiatry, 64*, 853–864. https://doi.org/10.1001/archpsyc.64.7.853.

Liu, K., King, M., & Bearman, P. (2010). Social influence and the autism epidemic. *American Journal of Sociology, 115*, 1387–1434. https://doi.org/10.1086/651448.

Lord, C., Risi, S., DiLavore, P. S., Shulman, C., Thurm, A., & Pickles, A. (2006). Autism from 2 to 9 years of age. *Archives of General Psychiatry, 63*(6), 694–701. https://doi.org/10.1001/archpsyc.63.6.694.

Lord, C., Rutter, M., DiLavore, P. C., & Risi, S. (2002). *Autism diagnostic observation schedule-generic (ADOS-G) manual.* Los Angeles, CA: Western Psychological Services.

Magiati, I., Tay, X. W., & Howlin, P. (2014). Cognitive, language, social and behavioural outcomes in adults with autism spectrum disorders: A systematic review of longitudinal follow-up studies in adulthood. *Clinical Psychology Review, 34*, 73–86. https://doi.org/10.1016/j.cpr.2013.11.002.

Mandell, D. S., Morales, K. H., Xie, M., Lawer, L. J., Stahmer, A. C., & Marcus, S. C. (2010). Age of diagnosis among medicaid-enrolled children with autism, 2001–2004. *Psychiatric Services, 61*(8), 822–829. https://doi.org/10.1176/appi.ps.61.8.822.

Mazurek, M. O., Handen, B. L., Wodka, E. L., Nowinski, L., Butter, E., & Engelhardt, C. R. (2014). Age at first autism spectrum disorder diagnosis: The role of birth cohort, demographic factors, and clinical features. *Journal of Developmental & Behavioral Pediatrics, 35*, 561–569. https://doi.org/10.1097/DBP.0000000000000097.

Oono, I. P., Honey, E. J., & McConachie, H. (2013). Parent-mediated early intervention for young children with autism spectrum disorders (ASD). *Evidence-Based Child Health: A Cochrane Review Journal, 8*(6), 2380–2479. https://doi.org/10.1002/ebch.1952.

Pinto-Martin, J. A., Dunkle, M., Earls, M., Fliedner, D., & Landes, C. (2005). Developmental stages of developmental screening: Steps to implementation of a successful program. *American Journal of Public Health, 95*(11), 1928–1932. https://doi.org/10.2105/AJPH.2004.052167.

Preeti, K., Srinath, S., Seshadri, S. P., Girimaji, S. C., & Commu, J. V. S. (2017). Lost time – Need for more awareness of early intervention in autism spectrum disorder. *Asian Journal of Psychiatry, 25*, 13–15. https://doi.org/10.1016/j.ajp.2016.07.021.

Rosenberg, R. E., Landa, R., Law, J. K., Stuart, E. A., & Law, P. A. (2011). Factors affecting age at initial autism spectrum disorder diagnosis in a national survey. *Autism Research and Treatment,* 1–11. https://doi.org/10.1155/2011/874619.

Rutherford, M., McKenzie, K., Johnson, T., Catchpole, C., O'Hare, A., McClure, I., xxx, & Murray, A. (2016). Gender ratio in a clinical population sample, age of diagnosis and duration of assessment in children and adults with autism spectrum disorder. *Autism, 20*(5), 628–634. https://doi.org/10.1177/1362361315617879.

Rutter, M. (2006). Autism: It's recognition, early diagnosis, and service implications. *Journal of Developmental & Behavioural Pediatrics, 27*(2), s54–s58. https://doi.org/10.1097/00004703-200604002-00002.

Rutter, M., Le Couteur, A., & Lord, C. (2003). *Autism diagnostic interview – Revised, vol. 29*, Los Angeles, CA: Western Psychological Services30.

Ryan, S., & Salisbury, H. (2012). 'You know what boys are like': Pre-diagnosis experiences of parents of children with autism spectrum conditions. *British Journal of General Practice, 62*, e378–e383. https://doi.org/10.3399/bjgp12X641500.

Shattuck, P. T., Durkin, M., Maenner, M., Newschaffer, C., Mandell, D. S., Wiggins, L., xxx, & Cuniff, C. (2009). Timing of identification among children with an autism spectrum disorder: Findings from a population-based surveillance study. *Journal of the American Academy of Child & Adolescent Psychiatry, 48*(5), 474–483. https://doi.org/10.1097/CHI.0b013e31819b3848.

Sheinkopf, S. J., & Siegel, B. (2004). Home-based behavioural treatment of young children with autism. *Journal of Autism and Developmental Disorders, 28*, 15–23. https://doi.org/10.1023/A:1026054701472.

Steiner, A., Goldsmith, T., Snow, A., & Chawarska, K. (2012). Practitioner's guide to assessment of autism spectrum disorders in infants and toddlers. *Journal of Autism and Developmental Disorders, 42*, 1183–1196. https://doi.org/10.1007/s10803-011-1376-9.

Vismara, L. A., & Rogers, S. J. (2010). Behavioral treatments in autism spectrum disorder: What do we know? *Annual Review of Clinical Psychology, 6*, 447–468. https://doi.org/10.1146/annurev.clinpsy.121208.131151.

Ward, S. L., Sullivan, K. A., & Gilmore, L. (2016). Practitioner perceptions of the assessment and diagnosis of autism in Australia. *Australian Psychologist, 51*, 272–279. https://doi.org/10.1111/ap.12211.

Whitehouse, A. J. O., Cooper, M. N., Bebbington, K., Alvares, G., Lin, A., Wray, J., & Glasson, E. J. (2017). Evidence of a reduction in the behavioural severity of autistic disorder diagnoses. *Autism Research, 10*, 179–187. https://doi.org/10.1002/aur.1740.

Wiggins, L. D., Baio, J., & Rice, C. (2006). Examination of the time between first evaluation and first autism spectrum diagnosis in a population-based sample. *Journal of Developmental and Behavioral Pediatrics, 27*, S79–S87. https://doi.org/10.1097/00004703-200604002-00005.

Wimpory, D. C., Hobson, R. P., Williams, J. M., & Nash, S. (2000). Are infants with autism socially engaged? A study of recent retrospective parental reports. *Journal of Autism and Developmental Disorders, 30*, 525–536. https://doi.org/10.1023/A:1005683209438.

Zuckerman, K. E., Lindly, O. J., & Sinche, B. K. (2015). Parental concerns, provider response, and timeliness of autism spectrum disorder diagnosis. *The Journal of Pediatrics, 166*(6), 1431–1439. https://doi.org/10.1016/j.jpeds.2015.03.007.

Zwaigenbaum, L., Bauman, M. L., Choueiri, R., Fein, D., Kasari, C., Pierce, K., xxx, & Wetherby, A. (2015). Early identification and interventions for autism spectrum disorder: Executive summary. *Pediatrics, 136*(Supplement 1), s1–S9. https://doi.org/10.1542/peds.2014-136S1.