

Parents' experiences of the service pathway to an autism diagnosis for their child: What predicts an early diagnosis in Australia?

Abstract

Background: The early identification and diagnosis of autism is critical to ensure access to appropriate early intervention and support. Few studies have examined the association between potentially modifiable characteristics of the service system and timelier diagnosis.

Methods: An online survey was conducted to examine parental experiences of service pathways to an autism diagnosis for their child, and to identify child, family, and service level characteristics that predict the age and timeliness of diagnosis. Participants included 107 parents of children with autism who were diagnosed by 7 years of age and a smaller subgroup of 29 parents who were diagnosed after 7 years of age.

Results: Parents of younger children reported that, on average, it took approximately 12 months and 8 professional consultations to receive a confirmed diagnosis for their child. Parents of older children, as well as those who reported they were a sole caregiver, or were advised by professionals to 'wait and see', reported more time between first raising concerns and diagnosis.

Conclusions: The findings reiterate the importance of proactive professional responses to parental concerns. They also highlight the need for standardised screening and assessment and professional development and training to build capacity in the sector to deliver timely and accurate autism diagnoses.

Key Words: Autism, autism spectrum disorder, diagnosis, parents, services

What this paper adds?

To our knowledge, this is the first study to examine parents' experiences of the service pathway to an autism diagnosis in Australia, and one of few studies internationally that has examined potentially modifiable characteristics of the service system associated with more timely diagnoses. The process of obtaining an autism diagnosis is complex, and parents reported that it took on average 12 months and eight professional consultations to receive a diagnosis for their child. Our findings show that professionals' initial responses to parents' concerns are important in predicting the timeliness of diagnoses. Only a minority of families reported that a screening tool or assessment was conducted when they first raised concerns, and passive responses, such as being advised to 'wait and see', were associated with longer waiting times. The majority of parents' reported feeling supported by their families and professionals throughout the process of obtaining a diagnosis but found it difficult to access the services they needed. Parents of older children reported feeling significantly less supported by professionals throughout the diagnostic process. These findings highlight the need to build capacity in the sector to deliver accurate and timely diagnoses through professional development and training.

Highlights

- It took 12 months and eight appointments on average to obtain an autism diagnosis.
- Passive responses (e.g., advising 'wait and see') predicted longer waiting times.
- Single parents reported that it took longer to receive a confirmed diagnosis.
- Parents of older children reported a longer time between raising concern and diagnosis.

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Parents' Experiences of the Service Pathway to an Autism Diagnosis: What predicts an early diagnosis in Australia?

1. Introduction

Autism spectrum disorder (ASD) is an umbrella term used to describe a group of neurodevelopmental conditions characterised by difficulties in social-communication and interaction as well as repetitive or restricted interests and behaviours, which are first evident from early childhood (American Psychiatric Association, 2013). The early identification and diagnosis of autism is critical to ensure access to appropriate early intervention and support services. Intensive early intervention leads to improvements in language, cognition and adaptive functioning for many children on the autism spectrum (Dawson et al., 2010; Perry et al., 2013; Rogers & Vismara, 2008), which may translate into substantial economic benefits for families and communities (Cidav et al., 2017). While support at any age is beneficial, younger children may benefit most from early intervention due to early brain plasticity (Dawson et al., 2012). Indeed, the age that a child commences early intervention, cognitive ability pre-treatment, and the amount of intervention received have been identified as important indicators of developmental gains (Clark et al., 2018; Flanagan et al., 2012; Perry et al., 2013; Smith et al., 2015; Vivanti et al., 2016).

Early behavioural markers of ASD, such as inconsistent or reduced: eye contact, orientation to name, use of gestures, social smiling, response to joint attention and imitation are evident from the first year of life (Barbaro & Dissanayake, 2009, 2010). Many children can be reliably diagnosed from 24 months of age, and research suggests these early diagnoses are stable into later childhood for 85-90% of cases (Barbaro & Dissanayake, 2016; Chawarska et al., 2007; Clark et al., 2016; Guthrie et al., 2012). Although feasible, the diagnosis of ASD in young children can be complex, due to marked variability in presentation and rapid development during the first years of life (Steiner et al., 2012). The diagnostic criteria acknowledges that for some children difficulties may not emerge until a

later age, when social demands exceed capabilities (American Psychiatric Association, 2013). Factors which may contribute to a child being diagnosed with ASD at a later age also include the type and severity of symptoms the child presents with, their developmental level, variability in symptom onset, fewer parental concerns and lower socio-economic status, together with the availability of diagnostic services and lengthy waiting lists to access these (Daniels and Mandell, 2014). Indeed an international literature review found that the average age at diagnosis reported across studies ranged from 38 to 120 months (Daniels & Mandell, 2014), highlighting the variability in families' diagnostic experiences. Similarly in Australia, the average age of diagnosis of autism is reported to be approximately 4 years of age in children younger than 7 (Bent et al., 2015) and 6 years in children aged up to 12 years (May & Williams, 2018).

Large surveys in the United Kingdom (UK) and United States (US) have investigated parents' experiences of the service pathway to an autism diagnosis, finding general dissatisfaction and long wait times throughout the pathway to diagnosis (Crane et al., 2016; Howlin & Asgharian, 1999; Howlin & Moore, 1997; Oswald et al., 2015; Zuckerman et al., 2015). Howlin and Moore (1997) examined the diagnostic experiences of 1295 parents enrolled with autism societies in the UK, over 20 years ago; the average age of diagnosis of children in this sample was more than 6 years, despite parents reporting first seeking help an average of 3 years and 9 months earlier. Crane and colleagues (2016) sought to replicate and extend on this study by conducting an updated survey of 1047 parents. The average age of diagnosis of children in this sample was 7.5 years, an average of 3.5 years after parents first reported seeking help from a health professional (mostly commonly general practitioners and health visitors). These findings suggest that there has been no substantial reduction in age of diagnosis in the UK since Howlin and Moore conducted their original survey. Indeed, a slight increase in the average age of diagnosis is evident over time, which may be attributable to the inclusion of more participants with Asperger's, some of whom may present with more subtle symptoms and experience a longer diagnostic delay (Crane et al., 2016). Across both

studies, greater parental satisfaction with the diagnostic process was associated with less time taken to receive a diagnosis (Crane et al., 2016; Howlin & Moore, 1997).

A recent New Zealand study of 516 parents (Eggleston et al., 2019) found that higher satisfaction with the diagnostic process was predicted by satisfaction with the diagnostic report, lower parent stress, less time spent on waiting lists, multidisciplinary assessment and absence of a concurrent ADHD diagnosis. Parents in this sample reported first becoming concerned about their child's development at a mean child age of 3.2 years, seeking professional advice (most frequently from General Practitioners, Paediatricians and Well Child Health providers) when the child was 3.5 years, and a mean age of diagnosis of 6.6 years. A relatively small proportion of parents in this sample (3.8%) were advised "to return if problems did not improve", while 13.8% were advised "not to worry" or "they'll grow out of it", which is concerning given that these families went on to receive a diagnosis.

Lengthy diagnostic delays were also reported in the 2011 Survey of Pathways to Diagnosis and Treatment, conducted by the Centers for Disease Control and Prevention in the US. This sample included 4032 parents of children with special health care needs aged 6 – 17 years ($n = 1420$ parents of children with autism). Parents of children on the autism spectrum reported becoming concerned about their child's development earlier than children with other developmental conditions; yet they received a diagnosis for their child at a significantly later age (ASD: $M = 62.8$ months; Other: $M = 55.4$ months). These parents were more likely to report that health care providers responded to their concerns in a reassuring or passive way (e.g., saying 'nothing was wrong' or that their child would 'grow out of it'), and these responses were associated with longer diagnostic delays (Oswald et al., 2015; Zuckerman et al., 2015). However, proactive responses to parents' concerns (e.g., referring to a specialist, conducting a developmental assessment) were associated with a more timely diagnosis (Zuckerman et al., 2015). Conducting a developmental or behavioural assessment, administering a screening tool, regular attendance at well-child health checks, and having to

consult fewer health professionals have also been associated with relatively earlier diagnoses (Daniels & Mandell, 2013; Goin-Kochel & Myers, 2004).

No known studies have investigated parents' experiences of the service pathway to an autism diagnosis in Australia and there is not one established pathway to care, with prominent state and provider-based differences. Parents may raise concerns with a primary health care professional (e.g., general practitioner or maternal and child health nurse), who may then refer to a paediatrician, families can also present directly to a paediatrician. Paediatricians can make a diagnosis and/or refer for further assessment to relevant allied health services (e.g., speech pathologist, occupational therapist, psychologist) or a multi-disciplinary assessment team (e.g., the Child and Adolescent Mental Health Service). It may also be the case that an education professional raises concerns with a parent, who may then seek further advice from a general practitioner or paediatrician.

Several reports have examined practitioners' perceptions of current diagnostic practices in Australia. The findings suggest that substantial variability exists, which may influence families' experiences of diagnosis by increasing uncertainty and impacting equitable access to post-diagnostic support. The use of standardised assessment tools in combination with clinical judgement can be an essential component of ensuring accurate and efficient diagnosis, particularly when a diagnostic decision is not clear. Indeed, the recently released National Guideline for the Assessment and Diagnosis of ASD in Australia (Whitehouse et al., 2018) recommends that information relevant to a diagnostic evaluation and assessment of functioning be collected in a structured way, and include standardised measures as appropriate. However, only 47% of 173 health professionals reported using a standardised behavioural measure (Taylor et al., 2016). Lengthy waiting lists to access initial Paediatrician appointments, as well as allied health and specialist assessment services have also been reported in Australia (Randall et al., 2016; Ward et al., 2016). Approximately one-third of Paediatricians reported that they made a diagnosis without input from allied health

professionals, and that waiting times to access assessments was the primary reason for not considering this information (Randall et al., 2016).

The findings to date highlight the need for ongoing research investigating the service pathway to an autism diagnosis in Australia, and barriers to a timely diagnosis. While a relatively large body of research has investigated factors associated with the age of diagnosis of ASD in recent years, few studies have identified modifiable characteristics associated with the service system (such as professional behaviour and responses to parent concerns). Furthermore, the majority of research in this area has been conducted in the UK and US, and further research is needed to ensure generalisability of these findings across samples and service settings. Therefore, the aims in this study were to (1) describe parents' service experiences of the pathway to an autism diagnosis in Australia, and (2) identify child, family, and service level characteristics that predict the age and timeliness of an ASD diagnosis.

2. Method

2.1 Participants

Parents and caregivers of children diagnosed with an ASD (since January 2008) living in Australia were invited to participate in the study. This period was selected to limit the impact of recall bias, and changes in the service environment prior to 2008 (when an autism-specific early intervention funding package was introduced in Australia, which provided up to \$12,000 to children with a documented diagnosis of ASD who were under 7 years of age). Parents and caregivers were recruited through an existing registry of research participants, service providers, autism associations and online communities who were contacted and asked to distribute information about the study (e.g., in e-newsletters).

Data were collected anonymously from 188 parents and caregivers between August 2014 and December 2015. Fifty-two participants were excluded from analysis as key items (e.g., age of diagnosis) were missing; this included 14 participants who reported that they suspected their child has ASD but they had not yet received a diagnosis. There was no

statistically significant difference in parent age ($t(165) = 0.527, p = .713$), annual income ($t(141) = 0.444, p = .725$), or years of education ($t(162) = -1.920, p = .847$), of respondents who did and did not complete the online survey. Respondents who reported that they had more than one child with ASD were asked to complete the survey regarding the experiences of their *youngest child*, to ensure that the sample included a mix of participants with and without an older sibling on the autism spectrum.

While parents of children of any age (who had been diagnosed since 2008) were able to participate, the majority of the sample were younger than 7 at the time of diagnosis. The sample was therefore divided into subgroups of younger ($N=107$) and older ($N=29$) children. As it may be difficult to generalise findings from the smaller number of parents of older children who described their service experiences.

2.1.1. Parent characteristics

Respondents were aged between 20 and 50 years ($M = 38.13, SD = 6.22$) with the majority being mothers (98%). Twelve percent (10%) of respondents reported speaking a language other than English at home, and 17% reported that they were born outside Australia. The majority of respondents indicated that they had completed some university education (66%), 13% reported living in a major city, 58% in a suburban area, and 29% in a rural or regional area.

2.1.2 Child Characteristics

The children reported on were aged between 2 years and 19 years 9 months at the time of the survey ($M = 7.66, SD = 3.60$), and included 72% boys. Among those children diagnosed prior to 7 years of age, the most commonly reported diagnosis was ‘autism spectrum disorder’ (60%), followed by ‘Asperger’s disorder’ (11%), ‘autistic disorder’ (11%), ‘high functioning autism’ (8%), and ‘pervasive developmental disorder – not otherwise specified’ (PDD-NOS) (5%). Thirty-six percent of children were reported to have a co-occurring developmental condition, including: developmental delay (17%), language delay (12%),

attention-deficit/hyperactivity disorder (12%), and anxiety disorder (8%), while 11% were reported to have had premature birth. The subsample of children diagnosed when they were older than 7 years had primarily received diagnoses of: Asperger's disorder (29%), autism spectrum disorder (24%), and high functioning autism (21%). The most frequently reported co-occurring conditions in this subgroup were anxiety disorder (20%) and auditory processing disorder (15%).

2.2 Measure

A purpose-developed online survey was used to examine participants' experience of the pathway to an ASD diagnosis, and to identify potential barriers and enablers to a timely diagnosis. The questionnaire included items from Howlin and Moore's (1997) original survey, adapted for the Australian service context. Additional items were also included following a comprehensive literature review of factors associated with the age of diagnosis of ASD. The survey included questions about family demographic characteristics, child characteristics and diagnoses, and service experiences from initial concerns to diagnosis, and was refined based on pilot testing with a small group of parents of children with ASD and experts in the field ($n = 11$).

2.3 Procedure

Ethics approval was obtained from the institution Human Ethics Committee, informed consent was obtained from all respondents and the survey was completed anonymously. Paper-based questionnaires were made available on request.

2.4 Analyses

The number of responses varied across the survey items (e.g., only participants who were referred to another professional completed the survey items regarding referral), so missing data were not imputed, and the relevant sample size is reported as appropriate. Descriptive statistics were calculated for all variables of interest. Two multiple regressions were conducted to predict (1) age of diagnosis, and (2) timeliness of diagnosis (time between first

seeking professional advice and obtaining a diagnosis). Variables that demonstrated statistically significant correlations with the dependent variables were included as potential predictors. Regressions were only conducted on the subsample of 107 children diagnosed when they were younger than 7 years. Including the smaller number of children who were older than 7 years at diagnosis resulted in a highly skewed distribution that could not be resolved through transformation.

Data were checked to ensure that there were no violations of assumptions. There was independence of residuals, as assessed by Durbin-Watson statistics. Linearity and homoscedasticity were assessed by plotting studentized residuals against unstandardized predicted values. There was no evidence of multicollinearity, as assessed by correlation coefficients and tolerance values. No significant outliers were identified based on studentized deleted residuals, leverage values and Cook's distance. The assumption of normality of residuals was met.

3. Results

3.1 Parents' Experiences of the Service Pathway to Diagnosis

3.1.1 First Professional Consultation

Parents' of younger children reported that they first sought professional advice when their child was an average of 29 months of age ($M = 29.39$, $SD = 16.48$). Parents most commonly reported first raising concerns with a general practitioner (30%), paediatrician (27%), or maternal and child health nurse (22%). The most frequently reported professional responses were to refer to another professional (54%), to acknowledge parents' concerns (49%), to advise 'not to worry' or that there was no problem (39%) or to 'wait and see' and return if problems persisted (35%). Parents reported waiting 7 days for their initial appointment (range 0 – 6 months), with most seeing a professional within one month (81%).

Among the subgroup of older children, parents reported that they first sought professional advice when their child was 48 months of age ($M = 47.97$, $SD = 27.89$), most commonly from a paediatrician (24%), and were frequently advised ‘not to worry’ or that there was no problem (41%).

3.1.2 Secondary Referral and Consultation

Parents of younger children were most commonly referred to a paediatrician (44%) for their second consultation, and children were reported to be an average of 35 months of age at the time ($M = 34.73$, $SD = 18.94$). During this consultation, professionals were most frequently reported to acknowledge parents’ concerns (60%), talk about autism (35%), raise concerns about child development (31%), and conduct a developmental assessment (26%). Parents reported waiting, on average, 28 days to attend this appointment (range 0 – 6 months). Among parents of older children, 28% ($n = 8$) reported that they were referred to another professional (commonly a psychologist or speech pathologist), and children were on average 8 years and 6 months of age at the time of this next consultation ($M=8.47$ $SD=4.18$).

3.1.3 Receiving a Diagnosis

On average, parents of younger children reported that their child received an autism diagnosis at 46 months of age ($M = 45.90$, $SD = 17.71$). The average (median) time between parents’ first concerns and seeking professional advice was 4.5 months (range: 0 – 64 months) and the average (median) time between first seeking professional advice and receiving a confirmed diagnosis was 12 months (range: 0 – 58 months). Throughout the diagnostic process, parents reported attending an average of eight professional consultations regarding their concerns about their child’s development or behaviour (range: 1 – 30), and 29% changed paediatricians during this process. Parents of older children reported that their child received a diagnosis at an average (median) age of 9 years and 4 months (range 7 -17 years). The median time between parents’ first concerns and seeking professional advice was 5.5 years (range: 3

months – 13 years) and the median time between first seeking professional advice and receiving a confirmed diagnosis was 4 years 10 months (range: 0 – 13 years).

Parents' rated their overall experience of the diagnostic process on a 6-point Likert scale ('strongly agree' (1) to 'strongly disagree' (6)). The majority of parents agreed that they felt supported by family members and professionals, disagreed that it was easy to access the services they needed, but agreed that obtaining a diagnosis helped their family access services and support (Figure 1). Mann-Whitney U tests were conducted to determine if there were significant differences between the ratings of parents of older and younger children. Parents of older children reported significantly less agreement with the statements that diagnosis had helped them access services ($U=654$, $Z=-3.64$, $p<.001$) and that they felt supported by professionals throughout diagnosis ($U=877$, $Z=-2.12$, $p=.034$). There were no significant differences in parents of younger and older children agreement with the accessibility of services ($U=966$, $Z=-1.54$, $p=.125$) or support from family members ($U=1083$, $Z=-0.76$, $p=.447$).

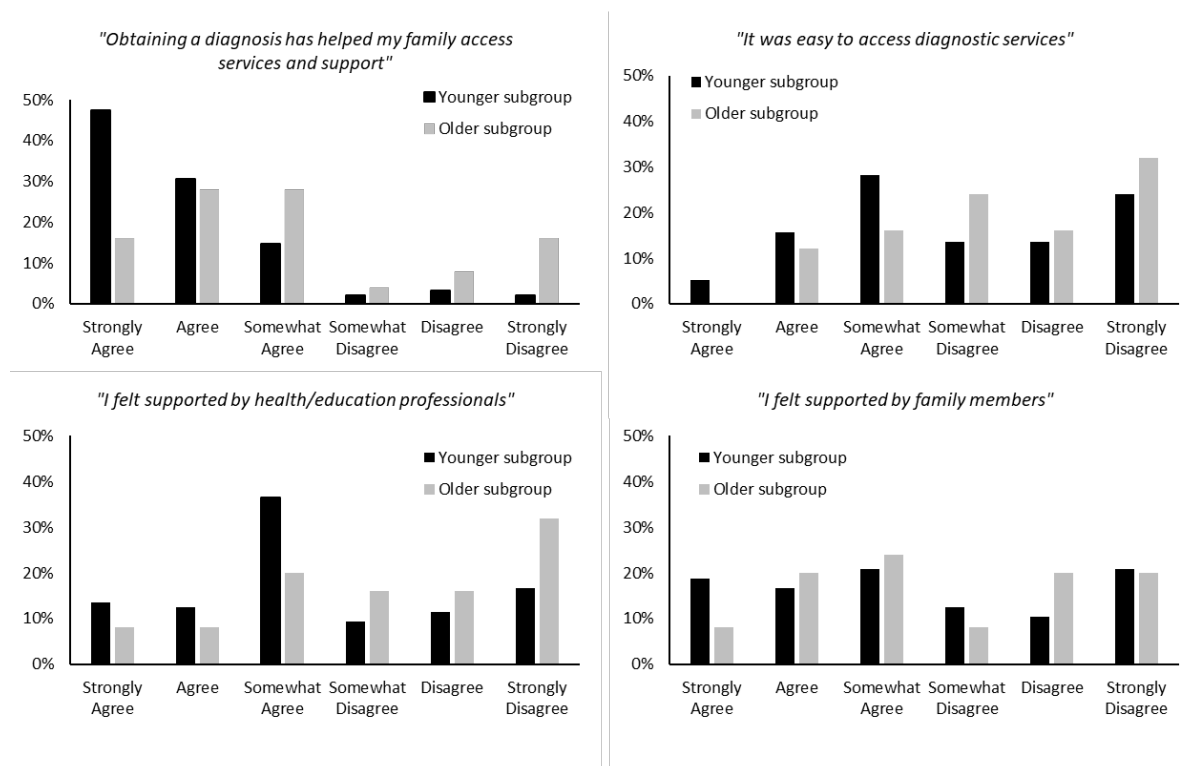


Figure 1. Parents' responses to 6-point Likert scales ('strongly agree' to 'strongly disagree') regarding their experiences of diagnosis. The younger subgroup included children aged less than 7 years at diagnosis ($n=96$). The older subgroup included children older than 7 years at diagnosis ($n=25$).

3.2 Predicting the Age and Timeliness of Diagnosis

A multiple regression was conducted to predict age of diagnosis. Age of concern, concerns about a child's social response, eye contact, and premature birth were entered into the model (as they were significantly correlated with the dependent variable). The model (Table 1) was statistically significant, $F(4,102)=14.76$, $p<.001$ and accounted for approximately 34% of variance in age at diagnosis ($R^2 = 0.37$, Adjusted $R^2 = 0.34$). Earlier age at first concern was the only significant unique predictor of an earlier diagnosis.

Table 1

Multiple regression predicting age of diagnosis

	<i>r</i>	B(SE)	Beta	<i>P</i>
Age of first concerns	.52**	0.63 (0.12)	.47**	<.001
Limited or inconsistent eye contact	-.34**	-5.83 (3.20)	-.17	.072
Reduced social response	-.27*	-5.22 (3.23)	-.15	.107
Premature Birth	-.24*	-8.46 (4.52)	-.15	.064

Note. $N = 107$, ** $p < .001$, * $p < .05$, *r* indicates Pearson Correlation Coefficient

The model predicting timeliness of diagnosis (time between first seeking professional advice and obtaining a diagnosis) contained six potential predictor variables that were significantly correlated with the dependent variable (Table 2). The model was statistically significant and accounted for 17% ($R^2 = 0.22$, Adjusted $R^2 = 0.17$) of variance, $F(6,85) = 4.02$, $p = .001$. Parents who reported that they were the sole caregiver, or were advised to 'wait and see', were more likely to report a longer time between first seeking professional advice and diagnosis. Concerns regarding a child's social response, being referred to another professional at the first consultation, parent satisfaction and needing to consult more professionals were correlated with the timeliness of diagnosis; however these latter variables were not significant unique predictors in the regression (Table 2).

Table 2

Multiple regression predicting timeliness of diagnosis

	<i>r</i>	B(SE)	Beta	<i>p</i>
Sole Caregiver	.19*	.10.74 (4.34)	.24*	.015
Parent advised to 'wait and see'	.28*	6.41 (3.22)	.23*	.040
Reduced social response	-.23*	-4.66 (2.71)	-.17	.090
Referral to another professional at first consultation	-.28*	-4.37 (2.90)	-.16	.135
Satisfaction with consultation	-.25*	-0.65 (0.93)	-.08	.485
Number of professional consultations	.19*	0.14 (0.28)	.05	.624

Note. $N = 92$, * $p < .05$, r indicates Pearson Correlation Coefficient

4. Discussion

In this study, we aimed to describe parents' experiences of the service pathway to an autism diagnosis in Australia, and to identify child, family, and service level characteristics that predict the age and timeliness of diagnosis. To our knowledge, this is the first study to examine parents' experiences of autism diagnosis in Australia and few international studies to date investigating factors associated with age of diagnosis have identified modifiable characteristics associated with the service system.

4.1 Parents' Experiences of the Service Pathway to Diagnosis

Parents of younger children (<7 years) reported first discussing their concerns with a health professional (mostly commonly a general practitioner, paediatrician or maternal and child health nurse) when their child was 29 months of age on average and receiving a diagnosis when their child was 46 months. The smaller subgroup of parents of older children (>7 years) reported first seeking professional advice when their child was 4 years of age and receiving a diagnosis, 4 years and 10 months later, on average. The average age of diagnosis of children in this sample is comparable to the average age of diagnosis in other Australian and international reports (Bent et al., 2015; May & Williams, 2018; Young et al., 2003). The

current findings suggest that for children younger than 7 years obtaining an autism diagnosis took an average of one year, from the time parents first sought professional advice. This reflects a comparatively positive service experience relative to the findings of a large survey of parents in the United Kingdom, which reported an average diagnostic delay of 3.5 years (Crane et al., 2016). However, the smaller subgroup of parents of older children experienced diagnostic delays comparable to the UK sample. This findings suggests that there is substantial room for improvement in facilitating timely and accurate diagnoses of autism in Australia, particularly for older children.

Parents in the current study reported attending an average of eight professional consultations before obtaining a diagnosis, this is comparatively higher than the average 4.5 professionals seen throughout the diagnostic process in NZ (Eggleson et al., 2019). However, this finding should be interpreted with caution, for example it is possible that some families in the current study had commenced early intervention services (e.g., speech therapy) prior to receiving a confirmed diagnosis, and these consultations may have been included in their total. Nevertheless, a large proportion of parents in the current sample were advised to “wait and see” (35%) or “not to worry” (39%). While the proportion of families advised that “there was no problem” or “not to worry” is similar to that reported in the recent UK survey (30%), a much higher proportion of parents reported that they were advised to ‘wait and see’ and return if problems persisted (8%; Crane et al., 2016). The more frequent adoption of a ‘wait and see’ approach in Australia may also have contributed to the higher number of professional consultations reported compared to other studies.

Only a small proportion of parents in this study reported that a screening tool was administered when they first discussed their concerns with a professional, and only half reported that a developmental assessment was conducted at any point within their first three consultations. Although this findings should be interpreted cautiously given that it is possible that parents may not have been aware that a screening tool or assessment had been conducted

and that the purpose of the assessment/screening tool may not have been clear. However, recent surveys of professionals in Australia have also reported that many practitioners do not utilise standardised assessment measures (Randall et al., 2016; Taylor et al., 2016). It is possible that low uptake of standardised assessment measures may be contributing to inconsistencies in diagnostic practice, as these can provide a valuable source of information to inform clinical decision making. These findings reiterate the need to implement the National Guidelines for autism diagnostic practice in Australia (Whitehouse et al., 2018).

Access to autism specific early intervention services is currently largely dependent on receiving a formal diagnosis. The majority of parents in this sample disagreed that it was easy to access the diagnostic services they needed and while many agreed that obtaining a diagnosis helped them access ongoing services and support for their child, the smaller subgroup of parents of older children reported significantly less agreement with this statement. Taken together we suggest that while receiving a diagnoses may facilitate access to support for many families (particularly of younger children) that the accessibility of diagnostic services, remains a substantial barrier to care.

4.2 Predictors of Age and Timeliness of Diagnosis

We also examined predictors of child age of diagnosis and timeliness of diagnosis. Child age at first parent concern was the strongest predictor of age of diagnosis, with parents who reported becoming concerned about their child's development at an earlier age obtaining an earlier diagnosis for their child. Parent concerns related to social responsiveness, limited or inconsistent eye contact and premature birth were significantly correlated with age of diagnosis, but were not significant unique predictors in the regression. Service level factors including being referred to another professional at the first consultation and higher parent satisfaction were correlated with a timelier diagnosis, while needing to consult more professionals was correlated with a relatively delayed diagnosis. Being advised to 'wait and see' or 'return if problems persisted' was a significant unique predictor in this analysis,

associated with a longer time between first seeking help and diagnosis. Family socio-economic characteristics were not related to child age of diagnosis; however, parents who reported they were the sole caregiver to their child reported a longer time between first consultation and diagnosis. A possible interpretation of this finding is that sole caregivers may have more difficulty navigating services and advocating for a specialist referral. No relationship was evident between the recency of diagnosis (i.e., the amount of time since receiving a diagnosis) and the age or timeliness of diagnosis in the sample, suggesting no substantial changes in practice over time.

Few studies examining factors associated with the age of diagnosis of children on the autism spectrum have identified potentially modifiable characteristics associated with the service system. The current findings highlight the important role that proactive professional responses to parent concerns have in facilitating earlier diagnoses (Zuckerman et al., 2015). However, parents and health professionals in Australia have both reported long waiting times for specialist assessments. Professional development and training activities that aim to build understanding of the behavioural presentation of autism and support the uptake of evidence-based screening tools within a developmental surveillance framework may also help to determine when further assessment is warranted and facilitate more accurate and timely referrals.

4.3 Limitations

It is important to acknowledge that this study was conducted with a relatively small self-selected sample, and the service experiences described may therefore not be representative of the broader population. While the participant characteristics indicate good representation of individuals from minority groups and parents living in both urban and regional areas, this was a highly educated sample and the majority of participants were mothers. We only included parents who reported that they had received a diagnosis for their child since 2008, however examining changes in the service environment and the impact of

such factors on parents' experiences of diagnosis would be a worthy area of further research. The inclusion of only a small subgroup of parents of older children (due to low participation) means that we need to interpret these findings cautiously, further research examining the experiences of these families, who may have experienced longer diagnostic delays, is warranted. Nevertheless, the current findings provide an informative snapshot of service experiences and potential barriers and facilitating factors to a timely autism diagnosis.

4.4 Conclusion

The process of obtaining an autism diagnosis is complex and the experience of navigating services places a lot of demands on parents. The current findings highlight that it is critical to build the capacity of the sector to deliver timely and accurate diagnoses. Professional education and training in the early signs of autism and use of appropriate and evidence-based assessment tools, while supporting professionals to respond proactively when parents' raise concerns may mitigate adoption of the 'wait and see' approach and facilitate timely diagnoses.

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