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Obtaining an autism spectrum disorder diagnosis and supports: New Zealand parents' experiences

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ABSTRACT

Background: This study explored New Zealand parents' experiences of obtaining an autism spectrum disorder (ASD) diagnosis for their child and aimed to identify factors that predicted parent satisfaction.

Method: Parents of ASD parent support groups were invited by email to participate in an anonymous online survey. Parents were asked to rate their satisfaction with a number of key aspects of the diagnostic process for ASD. Correlation analysis and ANOVA were utilized to explore possible associations between parent satisfaction and putative demographic and clinical factors and experiences. Multiple regression analysis was used to identify key predictor variables of parent satisfaction and stress.

Results: Parent (n = 516) satisfaction with the diagnostic process for ASD was endorsed by 53.1%. The strongest predictor was satisfaction with the diagnostic assessment report, followed by higher levels of parent stress. Higher satisfaction was also predicted by spending less time on a wait-list for assessment, multi-disciplinary assessment and the absence of concurrent ADHD. Most parents found the diagnostic process stressful. Only 23% of parents were satisfied with post-diagnostic supports, and just 19% their coordination.

Conclusions: Just over half of New Zealand parents are satisfied with the diagnostic process for ASD, despite most finding the process stressful. Streamlining referral pathways, reducing assessment wait-times and increasing rates of multi-disciplinary team assessment may raise satisfaction rates further. Receiving a satisfactory diagnostic assessment report appears to be of particular importance to parents. The very low rate of satisfaction with post-diagnostic supports indicates that further development of these services is a priority for NZ.

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1. Background

Parents recognize that obtaining an autism spectrum disorder (ASD) diagnosis potentially leads to both positive and negative outcomes for their child and family. Benefits include the promotion of understanding of their child by themselves and others, provision of appropriate treatment and supports, reducing parental feelings of blame, allowing the seeking of support from others with similar difficulties through support organizations and providing a means for advocating for improved services (Craddock & Mynors-Wallis, 2014). Early diagnosis of ASD ensures that appropriate accommodations and interventions commence as quickly as possible (Fernell, Eriksson, & Gillberg, 2013), making this a priority for parents. However, parents also often acknowledge concerns regarding negative effects of labeling and mixed feelings on receiving a diagnosis, including coinciding feelings of relief and grief (Mansell & Morris, 2004). The process of obtaining a diagnosis of an ASD is also very frequently a protracted and stressful experience for parents (Crane, Chester, Goddard, Henry, & Hill, 2016).

Service user reports and/or ratings are useful for measuring the quality of care and can provide important information about how services may be improved (Lloyd, Jenkinson, Hadi, Gibbons, & Fitzpatrick, 2014). A number of studies have examined parents' experiences of the process of obtaining a diagnosis of an ASD including a landmark study of 1200 parents in the United Kingdom (UK) (Howlin & Moore, 1997), a follow-up study of over 1000 UK parents (Crane et al., 2016), a French study of 248 parents (Chamak, Bonniau, Oudaya, & Ehrenberg, 2011), a Belgian study of 244 parents (Renty & Roeyers, 2006), a Singaporean study of 102 parents (Moh & Magiati, 2012), a Canadian study of 56 parents (Siklos & Kerns, 2007), and a survey of 494 parents of children with an ASD from five countries (Goin-Kochel, Mackintosh, & Myers, 2006). Although rates of parent satisfaction with the diagnostic process for ASD were not always reported (Chamak et al., 2011; Moh & Magiati, 2012), satisfaction rates from individual countries range from 35% reported by Crane et al. (2016) to 51% in the study by Renty and Roeyers (2006). These studies have also reported a range of factors associated with parent satisfaction. Although the age of the child at diagnosis and the duration of the diagnostic process were foci of interest in earlier studies, multiple regression analysis has not found either to be a strong predictor (Crane et al., 2016; Goin-Kochel et al., 2006; Moh & Magiati, 2012). In multiple regression analyses, parents' level of stress during the diagnostic process has been the most consistent predictor of (low) parent satisfaction (Crane et al., 2016; Moh & Magiati, 2012). Other predictive factors include satisfaction with the manner of the disclosing professional and post-diagnostic supports (Crane et al., 2016); seeing fewer professionals during the diagnostic process (Goin-Kochel et al., 2006); better collaboration with professionals and greater helpfulness of information provided at diagnosis (Moh & Magiati, 2012); and greater child communication difficulties and fewer behavioural issues (Siklos & Kerns, 2007).

It has been almost ten years since the launch of the New Zealand (NZ) ASD guideline (Ministries of Health and Education, 2008). Despite the funding of ASD coordinators to facilitate the coordination of assessment for ASD and post-assessment support services in all regions, a recent study of clinicians identified significant disparities in how ASD assessments are undertaken throughout New Zealand (Thabrew & Eggleston, 2018). Findings indicated that paediatricians or multidisciplinary child development teams assessed most pre-school children with suspected ASD, child and adolescent mental health services assessed most adolescents, while primary school-aged children were assessed by a combination of these services depending on locally agreed pathways. Less than 5% of children were estimated to have been assessed by clinicians in private practice. Long wait-times to assessment, a lack of access to multidisciplinary professionals including psychologists, speech and language therapists and occupational therapists, and under-funding of post-diagnostic supports were identified as key areas of concern. To date, no studies have been undertaken to explore the experiences of NZ parents of children and adolescents related to these diagnostic processes for ASD and the factors related to their satisfaction remain unknown. Given the cultural diversity of New Zealand, it is unclear whether diagnostic processes are working for all families, especially those of Māori and Pacific Island ethnicities who are considered to be at risk of disadvantage across economic, health and education domains (Health Committee, 2013).

The primary aim of this study was to explore the perspectives parents of children and adolescents with ASD from throughout NZ regarding their experiences of, and satisfaction with, the process of obtaining an ASD diagnosis and supports. The study also sought to identify parent, child, diagnostic and service delivery factors that were associated with parental satisfaction in order to inform recommendations for improved service provision. Because parent stress during the diagnostic process has been identified as a consistent predictor of parent satisfaction with the diagnostic process, the study aimed to examine parent stress and to determine key predictors of this. Lastly, the New Zealand satisfaction findings were to be compared with the findings from other countries where similar surveys have been undertaken.

2. Method

2.1. Participants

Members of Autism NZ, the largest national ASD support group, and five additional support groups for people with ASD were contacted via email with an invitation to participate in the study, along with a hyperlink to the survey. Eligible participants were parents or primary caregivers of children or adolescents with an official diagnosis of ASD. A total of 560 completed responses were received providing information on parents' experiences of, and satisfaction with, the diagnostic process for ASD. Forty-four responses were excluded as they were either not completed by a parent/primary caregiver or the child did not have a confirmed ASD diagnosis, leaving a final sample of 516.

2.2. Procedure

The study was carried out in accordance with the ethical standards of the New Zealand Health and Disability Ethics Committees (HDEC) and with the Declaration of Helsinki as revised in 2000. As the study was undertaken as an anonymous online survey with minimal risk to participants, HDEC advised that a formal ethics committee review was not required and that the study could proceed. Information describing the nature and purpose of the study was provided to participants, along with a statement advising that participation was entirely voluntary and that submission of the competed questionnaire would be taken to indicate informed consent. Contact details of the lead author were given in the event that participants had any questions, concerns or distress. Data collection ran for 12 weeks between November 2016 and February 2017.

2.3. Materials

The study utilized a similar methodology to that used by Crane et al. (2016) in the UK in order to improve standardization and to facilitate comparisons between rates of parent satisfaction and key predictors across both studies. Demographic information included information about the parent's relationship to their child, ethnicity, highest level of education and geographic location. Parents were asked about their child's current age; gender; age of first concerns regarding a possible ASD; age when a professional was first consulted; which professional was first consulted; the outcome of the first consultation; how many professionals they saw between the first professional and the final ASD diagnostic assessment (to a maximum of "6 plus" professionals); duration on a wait-list for ASD assessment; who made the ASD diagnosis; whether a diagnostic assessment report was provided (and satisfaction with this) and their child's current ASD diagnosis. Parents' satisfaction with the diagnostic process, post-diagnostic supports and their coordination were assessed using a 5-point Likert scale ("very dissatisfied" to "very satisfied"). The stressfulness of the diagnostic process was assessed using a 4-point Likert scale (1 = not at all stressful, 2 = not very stressful, 3 = quite stressful, 4 = very stressful).

A number of additional questions, which have not been previously investigated, but which were hypothesized to be potentially important aspects, were included. These included whether assessments were multidisciplinary, as recommended by New Zealand ASD guideline (Ministries of Health and Education, 2008); parents' estimate of the overall severity of their child's ASD utilizing the DSM-5 severity levels; whether comorbid psychiatric disorders (which commonly exist among individuals with ASD) had been diagnosed; and parents' satisfaction with the coordination of post-diagnostic supports. Survey questions were refined in collaboration with Autism NZ.

2.4. Data analysis

Statistical analysis was performed using SPSS v24.0. Correlation analysis (Spearman's Rho) and ANOVA were utilized to explore possible associations between putative demographic, clinical and diagnostic experiences and both dependent measures, parent satisfaction with the diagnostic process for ASD and parent stress during the process. Predictors identified from univariate analyses were then analyzed using multiple regression analysis to identify independent associations with parent satisfaction with the diagnostic process for ASD and for parent stress during the process. A two-tailed p-value < 0.05 was taken to indicate statistical significance.

3. Results

3.1. Parents' demographic information

Participants included mothers (87%) and fathers (8.5%) and other primary caregivers such as foster parents (4.5%). Most identified themselves as NZ European (80.6%), while 8.7% identified as Māori, 5.2% Asian, 2.9% Pacific Islander and 1.6% "other". NZ census (2013) statistics indicate that the NZ population is comprised of 74% NZ European, 15% Māori, 12% Asian and 7% Pacific people. Parents were largely well educated with 49.6% having attained a university degree or greater. Nineteen out of twenty NZ District Health Board regions were represented.

3.2. Children's demographic and clinical information

The mean current age of children was 12.3 years (SD = 6.7 years). Most were male (83.7%). Primary diagnoses included ASD (45.9%), Autistic Disorder (26.4%), Asperger(s) 18.6%, Pervasive Developmental Disorder - Not Otherwise Specified (3.7%) and Rett Syndrome (0.4%). Parents rated 40.7% of children as "requiring support" (mild), 36.0% as "requiring substantial support" (moderate) and 13.6% as "requiring very substantial support" (severe), while 7.8% were described as requiring little or no current support. Psychiatric comorbidities included anxiety disorders (26.9%), attention deficit hyperactivity disorder (24.6%), depression (8.1%), and conduct disorder/oppositional defiant disorder (5.8%). A further 21.7% had been diagnosed with "global developmental delay" and 13.8% intellectual disability, the majority of who had received a diagnosis of both.

3.3. Parents' experience of the diagnostic process

Parents' first concern(s) that their child may be on the ASD spectrum occurred at a mean age of 3.2 years (SD = 3.0 years), the

Table 1
Parent satisfaction scores (%) with various aspects of the diagnostic process.

	Very dissatisfied	Dissatisfied	Neither dissatisfied or satisfied	Satisfied	Very Satisfied
Overall diagnostic process for ASD (n = 516)	11.4	19.4	16.1	42.6	10.5
Diagnostic assessment report (n = 516)	3.0	6.0	15.4	43.5	32.1
Post-diagnostic supports (n = 487)	18.9	25.6	28.3	23.6	3.6
Coordination of post-diagnostic supports (n = 487)	18.4	30.0	31.6	17.8	2.2

mean age of first professional consultation was 3.5 years (SD = 2.3 years) and the mean age of diagnosis (n = 75) was 6.6 years (SD = 5.8 years). The first professionals most commonly consulted included General Practitioners (29.1%), Paediatricians (25.8%) and Well Child Health providers/Plunket Nurses (13.0%). The most frequent outcomes of this initial contact were referral to another professional (33.4%), followed by receiving an ASD diagnosis (15.0%). Only 3.8% were "told to return if problems did not improve", but 13.8% were "told there was 'no problem' or not to worry (e.g. 'they'll grow out of it')". An average of 4.5 professionals were seen during the diagnostic process. The mean time spent on a wait-list for ASD assessment was 5.3 months (SD = 1.8 months). Paediatricians working in the public system made the most ASD diagnoses (38.6%), followed by paediatricians in private (14.1%), child and adolescent psychiatrists (10.9%) and psychologists (7.4%). Multidisciplinary Child Development Services made a further 14.5% of ASD diagnoses. A multidisciplinary team had assessed children of 54% of parents. The majority of parents (86.6%) indicated that they had received a diagnostic assessment report.

3.4. Parents' satisfaction and stress

Parents' satisfaction with the diagnostic process for ASD and with other aspects is summarized in Table 1. Over half of parents surveyed (53.1%) reported being satisfied with the diagnostic process for ASD (satisfied or very satisfied responses combined), while 30.8% reported being dissatisfied (dissatisfied and very dissatisfied responses combined). Although 75.6% of parents were satisfied with the diagnostic assessment report, only 27.2% were satisfied with post-diagnostic supports and just 20% were satisfied with their coordination. Most parents found the diagnostic process stressful, of whom 40.4% indicated that it was quite stressful and 37.2% very stressful. A further 20.1% described the process as not very stressful and only 2.3% not at all stressful.

3.5. Association of parent, child and diagnostic factors with parents' satisfaction and stress

Higher levels of parent education were weakly negatively correlated with satisfaction with the diagnostic process for ASD ($r = -0.12$; $p < 0.01$). No other parent factors, including Maori and Pacific Island ethnicity, were associated with greater overall satisfaction with the diagnostic process. Parents of children who had comorbid global developmental delay/intellectual disability (combined) were as satisfied with the diagnostic process as parents whose children did not have these conditions. The only psychiatric comorbidity associated with reduced overall satisfaction was ADHD ($p = 0.012$). Parents of children assessed by a multidisciplinary team were significantly more satisfied ($p = 0.033$). The location of assessment had no effect on overall satisfaction, with parents of children diagnosed in public and private, or regional and main centres, being equally satisfied.

Correlations between parents' satisfaction with the diagnostic process for ASD and a range of other key variables are presented in Table 2. Parent satisfaction with the diagnostic process was strongly correlated with satisfaction with the diagnostic report, while moderate correlations were found with reduced parent stress during the process, increased satisfaction with post-diagnostic supports and also their coordination (all $p \leq 0.001$). A weak correlation was found for a shorter length of time spent on a wait-list for assessment and for seeing fewer professionals during the diagnostic process (both $p \leq 0.001$).

Parent stress during the diagnostic process for ASD was weakly inversely correlated with all of those variables found to correlate with parent satisfaction with the diagnostic process for ASD (see Table 2). However, a weak correlation was also found with increasing severity of the child or adolescent's ASD (all $p \leq 0.001$).

A multiple regression analysis investigating all significant correlates was performed to assess predictors of parental satisfaction

Table 2
Correlations between parent overall diagnostic satisfaction and other key variables.

	1	2	3	4	5	6	7
1. Overall diagnostic satisfaction							
2. Number of professionals seen	−0.18**						
3. Time on wait-list	−0.21**	0.23**					
4. Severity of ASD	0.02	0.04	0.05				
5. Stress during the diagnostic process	−0.41**	0.20**	0.16**	0.19**			
6. Satisfaction with the diagnostic assessment report	0.52**	0.04	−0.02	0.01	−0.18**		
7. Satisfaction with post-diagnostic supports	0.35**	−0.06	−0.04	−0.03	−0.22**	0.26**	
8. Satisfaction with coordination of supports	0.34**	−0.12**	−0.03	−0.09	−0.25**	0.23**	0.66**

** $P \leq 0.001$ (2 tailed).

Table 3
Multiple regression analyzing predictors of satisfaction with the diagnostic process.

Predictor variable	B	SE B	β	p	sr^2
Satisfaction with diagnostic assessment report	0.52	0.05	0.43	< 0.001	0.27
Stress during the diagnostic process	−0.37	0.06	−0.24	< 0.001	0.1
Wait-time to assessment	−0.02	0.01	−0.18	< 0.001	0.04
Satisfaction with post-diagnostic supports	0.19	0.04	0.18	< 0.001	0.03
Number of professionals seen before diagnosis	−0.07	0.03	−0.09	0.02	0.01

B = unstandardized beta coefficient; SE B = standard error B; β = standardized beta coefficient; sr^2 = unique variance explained by each predictor.

with the diagnostic process (Table 3). The model had an adjusted R^2 of 0.44 indicating that these factors accounted for 44% of the variance in parental satisfaction. Parental satisfaction with the diagnostic assessment report was the strongest predictor (adjusted $R^2 = 0.27$), followed, in order, by stress during the diagnostic process, shorter wait-times to assessment, satisfaction with post-diagnostic supports and fewer professionals seen during the diagnostic process.

A second multiple regression analysis identified that higher levels of ASD severity was the strongest predictor of parental stress, followed by poor coordination of post-diagnostic supports, seeing a greater number of professionals during the diagnostic process and a longer period spent on a wait-list for assessment (Table 4). The model had an adjusted R^2 of 0.15, indicating that these factors accounted for only 15% of the variance in parent stress.

4. Discussion

4.1. Main findings

To our knowledge, this is the first study to explore the perspectives of NZ parents regarding the diagnosis of children and adolescents with ASD. Although the mean age of parent concern regarding a possible ASD was 3.2 years, the mean age of first seeking help from a health professional was 3.5 years and the mean age of actually receiving an ASD diagnosis was 6.6 years, suggesting a considerable delay in accessing a timely diagnosis and early intervention. Over half of parents surveyed (53.1%) reported being satisfied with the ASD diagnostic process, a higher satisfaction rate than those found by similar studies from other countries.

4.2. Factors associated with parental satisfaction and stress during the diagnostic process

Multiple regression analysis found that parents' satisfaction with the diagnostic assessment report was the strongest predictor in this study of parents' overall satisfaction with the diagnostic process for ASD. This aspect has not previously been investigated. Notably, this was a stronger predictor than parent stress, the most consistently identified predictor in past studies and the strongest predictor in the study by Crane et al. (2016). This suggests that parents' satisfaction with the diagnostic assessment report may be of particular importance in relation to parent's satisfaction with the diagnostic process. Although copying diagnostic assessment reports to patients and/or their parents is not a practice requirement in NZ, it is a NZ ASD guideline recommendation (Ministries of Health and Education, 2008), and it appears to be common practice as evidenced by 86.6% of parents endorsing receipt of a report. A review found that receiving correspondence from clinicians increased patients' satisfaction with psychiatric consultation (Harris & Boaden, 2006). Receipt of a report was considered to aid patient understanding, facilitated more effective communication between patients and professionals, enabled empowerment and assisted with advocacy. Other aspects of diagnostic assessment reports are likely to be important and further research into this would be informative. An important possible reason is that it is likely to be helpful for parents to receive their child's diagnosis of ASD in writing as this can assist in advocating for increased supports. Additionally, the provision of a clear and appropriate management plan has been identified as an important aspect of the ASD diagnostic process (Gaspar de Alba & Bodfish, 2011). Diagnostic assessment reports typically include a management plan, providing parents with clarity about what treatment and supports are required and should be received. Supporting this, satisfaction with the diagnostic assessment report was positively correlated with parents' satisfaction with both post-diagnostic supports and their coordination (both $p < 0.001$).

Parent stress during the diagnostic process was a significant negative predictor of parent satisfaction with the ASD diagnostic

Table 4
Multiple regression analyzing predictors of stress during the diagnostic process.

Predictor variable	B	SE B	β	p	sr^2
Severity of child's ASD	0.02	0.04	0.20	< 0.001	0.05
Coordination of post-diagnostic supports	−0.10	0.03	−0.14	0.005	0.04
Number of professionals seen before diagnosis	0.08	0.02	0.16	0.001	0.03
Satisfaction with the diagnostic assessment report	−0.13	0.04	−0.17	< 0.001	0.02
Wait-time to assessment	0.01	0.00	0.10	0.037	0.01

B = unstandardized beta coefficient; SE B = standard error B; β = standardized beta coefficient; sr^2 = unique variance explained for each predictor variable.

process. This is consistent with multiple regression analysis of parent satisfaction conducted by two key previous studies (Crane et al., 2016; Moh & Magiati, 2012). Multiple regression analysis of parent stress during the diagnostic process found that the strongest predictor was increasing severity of ASD, although this only accounted for 5% of the variance. Other predictors of parent stress, suggesting significant difficulties with service delivery and referral pathways, included longer periods on a wait-list for assessment and seeing a greater number of professionals prior to diagnosis. The latter has been reported previously (Goin-Kochel et al., 2006; Moh & Magiati, 2012).

Although the duration of the diagnostic process has not been a strong predictor of parent satisfaction with the diagnostic process in multiple regression analysis in past studies (Crane et al., 2016; Goin-Kochel et al., 2006; Moh & Magiati, 2012), this study found that a longer duration of time spent on a wait list for assessment was a significant predictor of overall parent satisfaction. Thus, the length of time spent on a wait list for assessment may be a more important predictor of parent satisfaction than the overall duration of the diagnostic process. This suggests that attempts to address long waiting lists for the assessment of ASD are an important target for funders and providers of diagnostic services.

Satisfaction with post-diagnostic supports also contributed to parents' overall satisfaction with the diagnostic process, consistent with Crane et al. (2016). A key reason that parents seek an ASD diagnosis is to enable access to appropriate supports and this finding is therefore unsurprising. It is notable, however, that while 53.1% of parents were satisfied with the overall diagnostic process for ASD, satisfaction with post-diagnostic supports was considerably lower at 27.2% and similar to the 23% finding of Crane et al. (2016) in the UK. The availability, accessibility and usefulness of supports, as well as their coordination are likely to be the main contributing factors. This study investigated the coordination of post-diagnostic supports and found that only 20% of parents were satisfied with this aspect. Satisfaction with the coordination of post-diagnostic supports was strongly correlated with satisfaction with post-diagnostic supports. This finding could be expected given that parents often describe experiencing significant challenges navigating and accessing services for their child with ASD (Tehee, Honan, & Hevey, 2009).

Parents were also significantly more likely to be satisfied if a multidisciplinary team had assessed their child. The NZ ASD guideline recognizes that multidisciplinary assessment is recommended in preference to sole diagnostician approaches where feasible (Ministries of Health and Education, 2008). Additionally, parents are likely to value the comprehensiveness of a multidisciplinary assessment and this may also increase the likelihood of multidisciplinary interventions. While the severity of ASD was not found to be significant, parents of children with comorbid ADHD, but not other psychiatric comorbidities, were significantly less satisfied. There is evidence that children with ASD who also have ADHD are diagnosed later than those without, suggesting that diagnosis of this group may be more difficult and protracted (Brett, Warnell, McConachie, & Parr, 2016). Post-hoc analysis found that parents of children with comorbid ADHD saw a significantly higher number of professionals prior to diagnosis ($p = 0.011$), spent longer on a wait-list for ASD assessment ($p = 0.001$) and were less satisfied with post-diagnostic supports and their coordination (both $p < 0.001$). However, parents' level of stress throughout the diagnostic process was not found to be different ($p = 0.426$).

4.3. Findings relating to Māori and Pacific Island people

A key issue in NZ research relates to findings in relation to Maori and Pacific Island people. Māori and Pacific Island people in NZ are considered to be at risk of disadvantage across health, education and other domains and the need for services to be accessible and culturally centred has been highlighted (Report of the Health Committee, 2013). Although the frequencies of minority ethnicities did not entirely match NZ census figures (Statistics New Zealand, 2013) and some bias is anticipated, rates of parents' satisfaction regarding the diagnostic process for ASD were no different for those Māori and Pacific Island parents compared with others in the study. As such, this study provides preliminary evidence that diagnostic services for ASD in NZ may be equally acceptable to Māori and Pacific Island parents. However, further research involving more representative Māori and Pacific Island parent views is required to test this tentative finding.

4.4. Comparisons with the large UK satisfaction study of Crane et al. (2016)

The similar methodology of this study allowed direct comparisons of parents' satisfaction with the diagnostic process for ASD and a number of other key findings with the UK study of Crane et al. (2016) (Table 5). New Zealand parents were more satisfied with the diagnostic process for ASD than their UK counterparts, with 53.1% of NZ parents satisfied compared with 35% in the UK. Multiple

Table 5
Summary of key comparisons between the NZ and UK samples.

	New Zealand	United Kingdom (Crane et al., 2016)
Current age of child (years (SD))	12.3 (6.7)	11.8 (6.1)
Age at first consultation (years (SD))	3.5 (2.3)	3.9 (3.3)
Age at diagnosis (years (SD))	6.6 (5.8)	7.5 (5.0)
Satisfaction with diagnostic process (%)	53.1	35
Diagnostic process very stressful for parent (%)	37.2	56
Received an assessment report (%)	86.6	85
Satisfaction with post-diagnostic supports (%)	27.2	23

SD = standard deviation.

factors, including possible cultural differences, are likely to contribute to this difference. In terms of findings that may be relevant to this, only 37.2% of NZ parents found the diagnostic process very stressful compared with 56% in the UK study. NZ parents were also less likely to have been told there was "no problem" with their child at their first professional consultation than UK parents (13.8% compared with 30%). A previous study found that premature reassurance from professionals and dismissals of parental concerns regarding ASD were associated with greater parental feelings of frustration and distress (Ryan & Salisbury, 2012).

4.5. Limitations

There are a number of obvious sources of bias. While this is the 3rd largest study of its type, the response rate to this survey is estimated to be low and in the vicinity of 5% given that there were approximately 10,000 ASD support group members (although not all support group members are parents). However, it is noted that NZ has approximately 7% of the population of the UK, suggesting that the participation rate may be proportionally higher than in the Crane et al. (2016) study. Parents who belong to support groups are unlikely to be representative of all NZ parents of children with an ASD, illustrated by the finding that parents in this study were noted to be predominantly NZ European and highly educated. Parents may be more likely to participate if they had experienced particularly positive or negative diagnostic experiences. Although the sample size is larger than many previous similar studies, the size of the sample may have affected power in analyses involving smaller subgroups. A transcribing error led to the age of the child at diagnosis only being available for a subset of 75 children. Although this limited analyses relating to the age of the child at ASD diagnosis and the duration between parents' first concerns about ASD and diagnosis, these aspects have not been found to be predictors of parents satisfaction in multiple regression analyses in previous studies and this error dose not detract from the main findings of the study. The study relied on parents reporting on diagnostic processes that had occurred on average almost 6 years previously, which may have had an impact on the accuracy of the information provided. One significant limitation was that some factors that have been found to be predictive of parent satisfaction in some previous studies, such as better collaboration with professionals and greater helpfulness of information at diagnosis, were not evaluated. However, an important consideration with parent surveys is to ensure that they are not overly onerous and a balance between replicating important and consistent predictors, such parent stress during the diagnostic process, and evaluating some possible predictors that have been considered to be potentially important within the New Zealand context was sought. Finally the correlational design of the study does not allow causal relationships between the various identified aspects to be determined.

5. Implications

Overall, our findings suggest that a little over half of NZ parents of children and adolescents with ASD are satisfied with the diagnostic process, a higher rate than those found for parents in other countries where parent satisfaction has been studied. However, most parents found the process stressful, children saw an average of 4.5 professionals before diagnosis and the mean time spent on a wait-list for assessment was 5.3 months. Further work is required to streamline referral processes and reduce assessment wait-list times. If implemented, these measures are likely to increase timely access to early intervention, reduce parent stress and further improve parent satisfaction.

Only half of children were assessed by a multidisciplinary team, as recommended by ASD guidelines, but their parents were more likely to be satisfied, underscoring the importance of increasing rates of multidisciplinary assessment for NZ children with ASD. Parents of children with comorbid ADHD were found to be less satisfied with the diagnostic process. They also saw more professionals prior to diagnosis, waited longer for assessment and were less satisfied with post-diagnostic supports. The results suggest that particular attention should be given to streamlining pathways to assessment and bolstering supports for those children with possible ASD where ADHD is also a consideration. The provision of a diagnostic assessment report that is acceptable to parents appears to be a particularly important aspect of the diagnostic process and increasing diagnosticians' awareness of this finding would be constructive.

In contrast to the comparatively high rate of parent satisfaction with the diagnostic process, the very low rates of parents' satisfaction with post-diagnostic supports and their coordination indicate that considerable further development of these aspects is a pressing need. Co-design of services with families is likely to be an effective way to achieve these aims. Future research should include a more detailed exploration of the experiences of NZ families regarding obtaining an ASD diagnosis and post-diagnostic treatment and care.

Declaration of conflicting interests

The authors declare that they have no conflict of interest.

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