How does an autism diagnosis impact a child and their carer in regional Australia?

Abstract

Background

Autism spectrum disorder (ASD) is a common neurodevelopmental disorder. This study aims to investigate the impact of an ASD diagnosis on children and their carers from a regional/rural Australian perspective.

Methodology

A three-part survey development study included: 1) Semi-structured individual ASD carer interviews to identify common themes; 2) Survey development and testing; and 3) Online survey circulation to wider group of carers, for data collection and analysis.

Results

Transcripts from eight carer interviews guided the development of sixty-five survey questions. The survey was circulated to 316 carers of children diagnosed with ASD. Of the one hundred and one respondents, 95% were female, 86% regional and 12% were rural inhabitants. The average child's age at diagnosis was 6.64 years. Most carers (93%) reported that diagnosis of ASD met their goal, for some an improved understanding of their child's behaviour (39%) and allowing access to therapy (16%), government disability funding (NDIS) (19%) and learning support (9%). Some (44%) reported no downsides to an ASD diagnosis, however 38% reported fears of discrimination, particularly with future relationships (5%) and employment (14%). Barriers included waiting times (16%), costs of appointments (9.9%), and difficulty navigating through the health system (5.9%). Only five participants reported having no costs associated with appointments.

Conclusion

Carers had positive attitude and experiences regarding their child's ASD diagnosis. The benefits outweighing perceived harms. Barriers in accessing services included waiting times, out-of-pocket expenses, and travel distance.

Keywords: Autism Spectrum Disorder, Regional Australia, Diagnosis, Barriers, Qualitative Research

Brief Points

What is already known on this topic?

An estimated 1% of people in Australia live with autism spectrum disorder (ASD).

ASD is now the predominant diagnostic category on the NDIS, accounting for 35% of the 600,000 individuals accessing support.

Previous surveys of ASD relate to predominantly urban populations, advantaged in terms of access to diagnostic and treatment options.

What this paper adds.

Carers felt positive about their child's ASD diagnosis, with benefits outweighing perceived harms.

Major barriers in accessing ASD diagnosis and services include waiting times, out-of-pocket expenses, and travel distance.

More cost-efficient ways for providing access to timely diagnostic services and therapy across regional and rural Australia are required.

Introduction

Autism Spectrum Disorder (ASD), a common neurodevelopment condition, effecting approximately 1% of Australians (2018).[1] The prevalence of ASD increased by 25.1% between 2015-2018, with parents now self-reporting that 3.3% of 10–14 year-olds may be affected.[1, 2] This may partially be due to changes in the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) criteria, access to the National Disability Insurance Scheme (NDIS) and public awareness.[1, 3]

In Australia, an ASD diagnosis follows an assessment by a pediatrician, child psychiatrist or clinical psychologist, utilising DSM-V criteria.[3] Usually presenting in early childhood, affecting 3.5 times more males than females, and found in all ethnic and socioeconomic groups, ASD is considered a lifelong condition.[1, 2] Many parents identify symptoms in children under 24-months-old, with females tending to present later.[4] The average age at diagnosis is 46 months with parents citing inadequate access to services, training of doctors, public awareness, difficulty obtaining referrals and stigma as barriers to diagnosis.[5, 6] Timely diagnosis of ASD reduces parental stress and financial burden, especially once in receipt of early childhood intervention.[7]

The NDIS is the Australian federal government scheme to support individuals living with disability.[8] This funds intervention including speech and occupational therapists in addition to behaviour management, physiotherapists, social workers, and psychologists[8]. In some cases, other supports such as mentoring, respite care, equine, aqua, art and music therapy may sometimes be provided. The cost of ASD in Australia is estimated to be $34,900 per annum per individual for families.[9] In June 2021, 182,494 individuals accessing support had ASD, accounting for over a third of NDIS participants.[8]

ASD may be associated with higher rates of bullying, loneliness or discrimination.[10] Further hesitancy to assign diagnostic labels exists in populations where ASD understanding is lacking, such as Indigenous and Immigrant communities.[11, 12] Nevertheless, physicians believe an ASD diagnosis has positive treatment-related and psycho-relational implications.[13]

Urban Australians are known to have better health outcomes than those who live in regional and remote areas.[14] This study is the first to survey the attitudes and experience of families from a regional centre, serving approximately 180,000 people. Our aim is to investigate the impact of an ASD diagnosis with associated benefits and harms; and identify barriers this population experienced when seeking a diagnosis or accessing care.

Materials and Methods

Ethical approval was obtained from the local Research Ethics Committee (HREC/66292/AWHEC-2020-237023(v2)) which operates under the Australian National Health and Medical Research Council (NHMRC) National Statement on Ethical Conduct in Human Research. Written and informed consent was provided by all interview and survey participants.

Semi-structured interviews: Carers of a child (<18 years with ASD (DSM-V – level 1-3)), diagnosed through a regional paediatric clinic within the preceding three years, were invited to participate in interviews to help understand the impact of a diagnosis of ASD. Interviews were conducted by one researcher (AD) on *Microsoft Teams*. Five open-ended questions generated in-depth conversations about their experiences of achieving a diagnosis and its subsequent impact (*Appendix A*). From the recorded interviews, transcripts were prepared and thematically analysed, using *Braun and Clarke's* framework.[15]

Survey Development: Survey questions were developed specifically for this study, based on the interview themes and from similar, survey-based studies identified in a comprehensive literature review. The survey was formatted on *Qualtrics Survey Software (https://www.qualtrics.com/au/)*. The survey was reviewed by local experts and the ethics committee. Then refined to sixty-five questions covering five domains (Figure 1; *Supp 1*). The participants subsequently tested the survey for clarity and usability. They also provided the researchers with feedback and an opportunity for troubleshooting.

Survey distribution: The survey was advertised with posters and flyers in the local paediatric clinics. All carers of children receiving a diagnosis of ASD within the preceding 3 years were contacted. Eligible participants were identified by searching the electronic medical record (eMR) for Medicare item number 135. This is a Medicare billing code used by specialists in Australia for complex neurodevelopmental disorder (such as ASD) *(https://www9.health.gov.au/mbs/)*. Participants responded anonymously with informed consent. The survey was made available online and was open for 4 weeks, between June and July 2021. For those with multiple affected children, the respondents completed the survey regarding *their first child* to receive an ASD diagnosis.

Survey analysis: Responses to open-ended questions were analysed qualitatively, using Braun and Clarke's framework.[15] This promoted an exploratory style of analysis. Initially, the first researcher (AD) noted emerging patterns within the data which were assigned 'codes' relating to broader analytical themes. The codes were then reviewed and cross-checked by a second researcher (DN). Quantitative data were presented descriptively by calculating total counts, percentages, means and standard deviation. *IBM SPSS Statistics 27* was used for exploratory analysis of the quantitative

results, including Mann-Whitney U tests. Postcodes were input into the *Australian Statistical Geography Standard (ASGS) Remoteness Structure* (2016), accessible at https://www.health.gov.au/resources/apps-and-tools/health-workforce-locator. This provided a ranking on a scale from 1-5 (1=metropolitan area; 5=very remote area). Similarly, postcodes were input into the *Census of Population and Housing Socio-Economic Indexes for Areas* (SEIFA), specifically *Index of Relative Socio-economic Advantage and Disadvantage* (IRSAD) (2021) accessible at https://experience.arcgis.com/experience/32dcbb18c1d24f4aa89caf680413c741/. This provided a ranking of socioeconomic advantage or disadvantage on a scale from 1-5 (1=most disadvantaged; 5=most advantaged), relative to other Australians.

Results

Eight semi-structured interviews were conducted, with an average duration of 43 minutes. The carers responses informed the options for relevant questions within the questionnaire.

Three hundred and forty children diagnosed with ASD in the previous three years were identified, via eMR. Twenty-four carers were uncontactable. Three hundred and sixteen were sent an invitation for the survey. Of these one hundred and one (31%) carers responded (Table 1a). Ninety-six were female, 95% born in Australia, and 100% spoke English at home. According to ASGS, all except two participants were from inner regional (86.14%) and outer regional (11.88%) areas *(Appendix B)*. The average SEIFA was 2.38 (SD=0.89). Three identified as Aboriginal Australian (2.97%), whilst three others declined to identify on basis of race. Most participants (68.3%) had one child with ASD, the characteristics of these children are presented in Table 1b.

Forty-six percent of carers stated that their main goal in seeking an ASD diagnosis was '*to understand [their child] and their behaviour better'.* Some (38.6%) stated that this was also the main benefit. Other benefits are summarised in Figure 2. Most (86.1%) believed that it was beneficial to their child's learning at school.

Most families (73.3%) received a NDIS plan. This funded speech therapy (69.3%), occupational therapy (59.4%) and psychology (35.6%), among other services (Figure 3). On average, children accessed 2.40 (SD=1.24) NDIS services regularly with most carers (78.2%) finding these services beneficial.

Carers feelings at the time of ASD diagnosis included relief (33.7%), grief/sadness (24.8%), worry for their child's future (23.8%) and optimism (22.8%). Some were optimistic that the diagnosis allowed access to therapy (43.6%). Others were sad (7.92%), worried (6.93%) or angry (3.96%) due to the

challenge of managing their child's behaviour, accessing services or therapy. Figure 4 displays some quotes from carers explaining their feelings.

Forty-two percent reported no concerns or negative experiences regarding their child's diagnosis. Forty-three percent identified some downsides to the ASD 'label'. These included social challenges (37.6%), stigma (24.8%), concerns regarding future employment (13.9%), relationships (4.95%) and bullying (6.93%). Nine carers (8.91%) mentioned personal challenges, including the child's self-image (6.93%) and behaviour (1.98%). A few (3.96%) felt the diagnosis was not worthwhile. One carer acknowledged that it is "not so much the 'label' but the disability itself" that causes difficulty. Twenty-eight carers (27.8%) stated that their child had experienced stigma, whilst 16 (15.7%) felt that they were treated differently because of their diagnosis. This was generally attributed to being generalised, underestimated, or misunderstood.

Half of the carers (50.5%) experienced barriers when seeking a diagnosis of ASD (Figure 5). The average age of presentation to a Paediatrician was 4.18 years with a diagnosis at 6.64 years (SD=2.59 years). Females were diagnosed 14 months later than males, this was statistically significant according to Mann-Whitney U Test. Waiting times (15.8%) and out-of-pocket appointment costs (9.90%) were reported barriers. Twenty-eight participants (27.7%) received publicly funded multidisciplinary assessments, but only five participants reported no out-of-pocket costs. The average diagnostic cost was over $2,000 (SD $1390.49), with a maximum of $8,000. Participants travelled a cumulative 90.2km on average (SD=96.87) to attend appointments for assessment. Other impediments including 'COVID-19 lockdowns' (17.8%), 'long wait times to access therapists' (14.9%), 'lack of suitable services' (8.9%) and 'difficulty navigating the system/finding providers' (5.9%) may have resulted in under-utilisation of NDIS plans.

Forty-two participants believed that there is a better way of diagnosing children with ASD. Some suggestions included "make testing cheaper", "roll it and the NDIS together" or "have the assessment funded through Medicare, or even a payment plan system would have helped my family so much". Others noted "we need more paediatricians and child psychologists" and "cut waiting times". Some participants suggested "specialty centres" or "a one stop shop under one roof where the professionals share their findings to make the process simpler and quicker" *(Appendix C)*.

Discussion

This is the first study investigating the impact of ASD diagnosis in a regional Australian population. We found that the ASD diagnosis helped carers understand their children, better manage their behaviour, whilst providing emotional and financial relief.

The carers reported that the benefits of an ASD diagnosis outweighed their perceived harms. Their diagnosis helped with their child's learning at school. NDIS funding provided a wide range of allied health services, with at least one type of therapy provided per child. Many reported no concerns about or negative experiences from their child's ASD diagnosis. However, some carers believed the 'label' affected relationships, education, and employment. Barriers to achieving a diagnosis included travel distance, waiting times, out-of-pocket expenses, and the lack of publicly funded services.

Our study was based on carers' experiences, from one regional centre. The response rate of 31% represents a small proportion of affected individuals and is vulnerable to bias. As with any self-selecting sample, we were not able to establish if the carers experiences were different to non-respondents. It is plausible that those who had particularly good or bad experiences preferentially completed this survey. Additionally, a common issue with self-report data is the susceptibility to social desirability bias.

The original design was for the interviews to be face-to-face in small groups. However, due to local pandemic restrictions, we moved to an online format. This may have excluded individuals who lacked resources in time and connectivity. Circulating the questionnaire online may also have attracted better resourced carers.

The bespoke survey tool used in this study generated valuable qualitative and demographic data, However due to its length, there were missing data. These were excluded from our analysis. Local experts reviewed the questions and pilot participants evaluated the survey tool prior to circulation. However, consultation with experts in survey development to remove ambiguity may have improved the surveys uptake and reliability..

Other studies have investigated the views of clinicians,[13, 16] carers in metropolitan areas[17, 18] or overseas.[4, 19, 20, 21, 22] Our study indicates a lag in achieving a diagnosis, which may reduce access to early childhood intervention services that are essential in minimising long-term symptom severity.[23]

Like other survey-based ASD studies most participants were female.[17, 20, 21, 22] The average age of their child's presentation at 37 months and diagnosis at 6 years corresponded to similar studies,[17, 19, 20, 21] but was later than other reports.[4, 17, 18] Perhaps indicating additional barriers to accessing a diagnosis in this regional and rural cohort. We did not record sociodemographic information for non-respondents

and therefore cannot fully assess the effect of participation bias; however, our sample appears to be more disadvantaged than the average Australian in terms of distribution by SEIFA scores. We found evidence that females were diagnosed later than males as shown elsewhere.[1, 2, 4] As in other studies most participants found the process stressful.[20, 22] Better financial and emotional support for carers may improve their experience. This could include government funded ASD assessment, parents support group, and more accessible information.

Our study suggests that the benefits of an ASD diagnosis (DSMV- Level 2 or 3) outweigh harm. These individuals are eligible for NDIS support in Australia and the families may also be eligible for government-funded Carers allowance and a Health Care Card for medication. Paediatricians should be cognisant to the carer's mental health, encouraging them to seek support through their GP or mental health services as required. Carers experience barriers to achieving an ASD diagnosis, including waiting times, costs of appointments and lack of government ASD services.[5, 14, 16, 21] Many participants in our study travelled over 90km to attend all the appointments necessary for diagnosis; a few travelled over 300km. In regional Australia many paediatricians work in private outpatient clinics, increasing the costs of assessment to local families. Most ASD diagnoses were concluded in a private paediatric clinic setting, the minority being made through public funded services.

While many carers denied disadvantages, others noted that their child had experienced social challenges, including employment concerns, bullying, or issues with self-image. An autism diagnosis may lead to discrimination from peers and employers. Blumberg et al. investigated the possibility of losing the diagnosis following developments in ASD research, effective intervention, and diminution of symptoms.[24] This option may minimise the potential long-term harms from an unwanted diagnosis.

As the cost of the NDIS in Australia escalates, more effective options of service provision are needed. As participants suggested, a more streamlined and affordable system is required to prevent excessive stress on families undertaking this process. Policy makers should consider increasing publicly funded community child health services and provision in schools, to enable all young people with development issues to access care regardless of a specific diagnosis. Therapy should be provided in a timely, needs and evidence-based manner. With the anticipated evolution of NDIS services and funding, further patient satisfaction surveys from regional and rural populations may be helpful.

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