Original Report

Diagnosing autism: contemporaneous surveys of parent needs and paediatric practice.

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Abbreviations: APRN: Australian Paediatric Research Network; ASD: Autism spectrum disorder; PDD-NOS: Pervasive Developmental Disorder; NESB: Non-English Speaking Background; SD: Standard deviation; SEIFA: Socio-Economic Indexes For Areas

Key Words: Autism spectrum disorder; parent survey; paediatric; Australian Paediatric Research Network

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ABSTRACT

Objective: Concurrence between parents' information needs and clinicians' practice when diagnosing autism is unknown but may influence families' uptake of management and adjustment. We aimed to: (1) compare parents experience and preferences with paediatrician report of (a) diagnosis delivery and (b) information given at diagnosis, and (2) identify types and usefulness of resources accessed by families post-diagnosis.

Design: Parent and paediatrician surveys.

Participants: Parents of children aged 1.5-18 years, diagnosed with autism between 01-Jan-2010 and 30-Sep-2012 and their paediatricians who are members of the Australian Paediatric Research Network.

Main outcome measures: Study-designed quantitative and qualitative questions about diagnosis delivery and information given at diagnosis (written and spoken vs. neither) and parent perceived importance and harms of information accessed post-diagnosis.

Results: 53/198 (27%) paediatricians identified 1127 eligible families, of whom 404 (36%) participated. Parents were more likely to report receiving adequate time to discuss diagnosis than paediatricians (71% vs 51%). Parents (98%) rated information about accessing allied health professionals and the meaning of diagnosis as most important yet paediatricians offered written or spoken information about each infrequently (allied health: 22%; diagnosis: 42%). Post-diagnosis, allied health was the most important source of information (83%). Harmful resources conveyed helplessness or non-evidenced based therapies but few parents (14%) reported this.

Conclusions: Parents want more information than can be conveyed in a single diagnostic consultation. Developing a tailored 'autism action plan' with written materials could improve parents' understanding of and satisfaction with children's autism diagnoses.

INTRODUCTION

Autism Spectrum Disorders (ASDs) are a group of neurodevelopmental disorders characterised by qualitative impairments in interaction and restricted, repetitive patterns of behaviour present from childhood.(1) The prevalence in Australian school-aged children is between 1.5% and 2.5% ,(2, 3) similar to international data.(4) In Australia, ASDs are usually diagnosed by general paediatricians working alone or within multidisciplinary teams, in private rooms, community health centres or hospital outpatient settings.(4) At diagnosis, the paediatrician's role includes explanation and documentation, and referral to activate government funding sources for intervention and support. From a paediatrician's perspective, delivering the diagnosis is challenging and emotionally-charged, as families are often distressed and craving information. The dearth of information on ASD aetiology, long-term prognosis, and a limited evidence base for interventions also make it difficult for paediatricians to provide information and answer families' often complex questions.(5)

From a parent's perspective, a child's ASD diagnosis has broad medical, financial, psychosocial, and time impacts. However, little is known about whether the delivery of the diagnosis and the information given at diagnosis meets parents' needs, or how it affects their engagement with support and services.(6) Small Australian,(7) British,(8) and American surveys(9) have found that parents' satisfaction at the time of diagnostic disclosure improves when they receive more information about ASDs and feel that clinicians understand their concerns. However, in a US sample of 146 ASD caregivers, only 40% of parents said clinicians spent time discussing ASD and provided information about available resources. Similarly, in a UK survey (n=68), 87% of mothers said they received inadequate advice on the best way to help their child.(10)

These experiences continue after the diagnosis, when families are often eager to commence intervention and will seek information from other sources including the internet and allied health professionals.(11) In a UK study of children diagnosed with ASD by a district service, families reported that their need for information about local resources was frequently unmet.(12) This finding is supported by a small Australian qualitative study where parents (n=32) revealed they often felt abandoned and confused about where to go next after the diagnosis and valued highly specific, personalised information.(13) No studies have asked parents whether information given at or accessed after diagnosis is harmful.

Further, no studies have investigated the agreement or otherwise between parents' information needs and clinicians' practice, both at and after an ASD diagnosis. Understanding this may help clinicians tailor their consultation to provide optimal support while managing families' expectations about the usefulness of information available. Therefore, in a sample of Australian families of children diagnosed with ASDs and their paediatricians, we *aimed* to:

1. Compare the experience and preferences of parents with their paediatrician's report of:
 - a. Diagnosis delivery;
 - b. Information given at diagnosis, including importance and perceived harm (parents only); and
2. Identify the types and perceived usefulness of resources accessed after diagnosis (parents only).

We hypothesised that parents and paediatricians would experience inadequate time for communicating the diagnosis; would receive/give considerable information, most of which is

not harmful but lacks individual care planning and written resources; and that parents would frequently access internet resources of variable usefulness.

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METHODS

Design and Setting: The Australian Paediatric Research Network (APRN) facilitates multi-site research of common childhood conditions in paediatric hospital outpatient, community, and private practice settings.(14) Australian states and territories are proportionally represented by APRN membership, and members and non-members are broadly similar other than minor differences in age, gender and practice location.(15, 16)

Participants and procedures: All APRN members were emailed to indicate their interest in participating given that not all members see children with ASDs. Paediatricians who expressed interest (n=141) plus those who saw children with ASD in a 2008 national practice audit (n=57)(17) were invited to identify eligible participants from their clinic records. Eligible participants were parents of children aged 18 months to 18 years who received an ASD diagnosis between January 1st 2010 and 30th September 2012 (recruitment period August 2011 to August 2013). The diagnosis was based on a DSM IV diagnosis and thus included Autism, ASD, Asperger's and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS). Families with insufficient English to complete the survey were excluded (identified by recruiting paediatrician or research team during survey reminder calls)

Participating paediatricians mailed parents a pre-prepared letter describing the study and asking families to opt-in or out (depending on ethics approval for their region). Parents who opted-in or did not opt-out after two weeks were mailed a pack with study information, parent survey, and reply-paid envelope. Reminder processes included sending another pack three weeks later and telephoning families two weeks after that.

Measures (study-designed): The *parent survey* asked about the child's diagnosis, whether a support person or the child was present at diagnosis, whether it was explained to the child, and parental satisfaction with these (yes/no). Parents rated 23 aspects of information received at diagnosis including how it was conveyed (written/spoken/not given) and whether it was important (yes/no). The information covered six themes: diagnosis (4 items, e.g. what diagnosis means), prognosis (2 items, e.g. future expectations), early intervention and therapies (6 items, e.g. tailored therapy plans), school support (3 items, e.g. explaining diagnosis to school), financial assistance (4 items, e.g. rebates from the Australian health care system), and support services and information resources (4 items, e.g. contact details for allied health professionals with ASD experience). As providing families with written and verbal information is considered best clinical practice,(18) we present data for the "both written and spoken" category only. Parents were asked for three important pieces of information that should be discussed and responses were qualitatively synthesised into the six aforementioned themes.

Using a 4-point scale (dichotomised into "essential/very useful" versus "quite useful/not useful"), parents rated 13 information resources used after the diagnostic consultation, including informal (e.g. other parents), health professionals, websites, and autism-specific support (e.g. parenting workshops). In open-ended questions, parents reported if any of the information was harmful or distressing.

A pilot study (unpublished) by Coates et al also surveying families' information needs in 2010 was used to assist in questionnaire design.

To compare parent preferences and paediatrician practice, paediatricians of families who completed the parent survey were invited to complete an online survey about their clinical practice. Paediatricians reported how they conveyed the information (e.g. written and spoken vs. none) on the same 23 information resources as parents, whether they made the diagnosis with the child or a support person in the room, and whether they had enough time to discuss the diagnosis with families. We piloted our measures for face validity with x practising paediatricians.

Parent and paediatrician practice postcodes provided an indicator of social disadvantage via the Australian Socio-Economic Indexes For Areas (SEIFA) Disadvantage Index (national mean 1000, SD 100; higher values represent greater advantage).(19) We categorized SEIFA into tertiles (low/medium/high socioeconomic disadvantage).

Statistical analysis: We used means (SDs) to describe and two-sided t-tests to compare continuous data, and proportions to describe and Pearson chi-square tests to compare categorical data. All quantitative analyses were performed using Intercooled Stata, v12.1 for Windows (Stata, College Station, TX, USA). Qualitative data were analysed via thematic grouping of responses based on the broad themes used in quantitative questions.

Ethical approval: The Human Research Ethics Committees of The Royal Children's Hospital (#31175A), Southern Health (#10318B), Victoria and Metro South Hospital and Health Service, Queensland (#12/QPAH/242) approved the study.

RESULTS

Participant Characteristics: 53/198 (27%) paediatricians identified 1268 patients.

Of these, 142 (11%) were ineligible (82 diagnosed before 2010, 44 not contactable, 10 no ASD diagnosis (parent report), and 10 insufficient English). Of the remaining 1126 eligible families, 404 (36%) responded; 187 (17%) declined; and 535 (47%) did not respond.

Respondents were more likely than non-respondents to have sons diagnosed with an ASD (85% vs. 69%; $p=0.01$) but there was no difference in SEIFA ($p=0.2$). Of participating families (Table 1), the mean child age was 7.1 years (SD 2.9 years) and most attended a mainstream school or preschool/kindergarten (81%). Parents were predominantly the birth mother (96%), partnered (88%), with a mean age of 38.5 years (SD 5.6 years).

Of the 53 paediatricians who identified eligible patients, 43 (81%) completed the paediatrician survey. Responding paediatricians compared to non-responders were more likely to work in a community health centre (16% vs. 6%, $p<.05$) and practice in the state of Victoria (58% vs. 26%, $p=.005$) but did not differ on other demographic (age, gender) or practice (private vs public, full vs part time) characteristics.

Aim 1a. Diagnosis delivery: While most parents reported adequate time to discuss the diagnosis (71%) and ask questions (76%), only half (51%) of paediatricians felt the same. Parents who had a support person present (56%) were overwhelmingly satisfied with this (99%) compared with parents who did not (61%). Most paediatricians (77%) reported trying to give the diagnosis with a support person present. Most parents received the diagnosis with their child present (62%), but satisfaction was high whether this occurred (87%) or not (96%). Only 8% of parents reported that the diagnosis was explained to the child. Parents were more likely to be satisfied when this happened (94%) than when it did not (25%). There

was a trend for older children and those with an Asperger's/high functioning ASD diagnosis to receive an explanation of their diagnosis.

Aim 1b. Information given at diagnosis: Table 2 describes parent and paediatrician report of information provided at diagnosis. Most parents rated all aspects of information as important (75%-98%); particularly allied health professionals with ASD experience and the meaning of the diagnosis. Parents and paediatricians broadly agreed on the frequencies for which written and spoken information were provided. The greatest discrepancies were that more paediatricians reported giving information about allied health professionals and funding rebates than parents reported receiving, and more parents reported receiving information on how the diagnosis was made than paediatricians reported giving. Further, parents reported not receiving information about the prognosis (38.8% vs. 16.3%, $p=0.04$) and contact details for parent support groups (48.5% vs. 25.6%, $p=0.04$) more than paediatricians reported not giving.

There was a mismatch between information parents reported as important and what they received from the paediatrician. This was greatest (ie >70% of parents reported not receiving the information despite saying it is important) – for school support (e.g. choosing a school, school disability funding, explaining the diagnosis to the school), ways to explain the diagnosis to their child, early interventions and therapies (e.g. tailored therapy plan, knowing which therapies are most effective) and alternative therapies. Furthermore, 96% of families said discussing a tailored therapy plan was important but 67% said this was not done.

Parents' qualitative responses revealed a similar pattern. The most important information to receive included tailored interventions and therapies (50%), prognosis (40%) and explaining the diagnosis (29%). The following comments reflect parents' concerns:

“I often found it hard to get any information specific to my son’s needs”

“We have personal trainers for getting fit that can tailor a program to the individual but we still can’t get that in our education system”

Half (48%) of parents said that information given at the time of diagnosis was distressing. However, only 7% reported information to be harmful, particularly if the information given was pessimistic or inadequate.

Aim 2. Information sought after diagnosis: Parents reported that allied health professionals (speech pathologists, psychologists and occupational therapists) were by far the most useful source of information (83%; see Table 3). Half (53%) said web resources were helpful. Fourteen percent of parents said information they sought was harmful, most of which was from websites and media that portrayed negative stories and causes/treatments that were not evidence-based.

DISCUSSION

Parent and paediatrician report of diagnosis delivery and information accessed were broadly similar. Most parents felt they had adequate time to discuss their child's ASD diagnosis although paediatricians want more. Having a support person present improved parent satisfaction with diagnosis and most paediatricians reported doing this. Parents valued highly the six themes of information surveyed and, while paediatricians gave families at least some information on most, they rarely followed best practice by giving both written and spoken information. Allied health professionals were the most valued source of help post diagnosis and most sources accessed by parents were not viewed as harmful.

This is the first study to assess agreement between parent information needs and paediatrician practice at ASD diagnosis. Despite recruiting a larger parent sample than previous surveys,(7, 9, 12) the proportions of responding parents and paediatricians were low. Time constraints may be a factor given the complexity of caring for a child with ASD and of paediatric practice. However, a diverse socio-demographic sample of Australian families participated, with quantitative data supported by qualitative analyses, suggesting that the findings should generalise to English-speaking Australian families. Similarly, we recruited a diverse group of paediatricians and results are likely to generalise to both private and public practice.

We did not directly observe consultations between paediatricians and families which, together with the time lag, may have led to response and recall biases by paediatricians and families. Paediatricians are likely to tailor their practice to the individual family in front of them and this could not be captured in the paediatrician survey. We used study designed

measures in the absence of validated measures but piloted our measures for face validity with practising paediatricians.

Unlike previous studies, most parents reported adequate time to discuss the diagnosis.(9) However, our findings match Bromley's (2004) study of 68 parents of children with ASD, where 79-87% of families valued information on how to help their child including services available.(10) They are also consistent with Whitaker's (2002) and Abbott's (2013) findings that ASD internet resources are highly accessed by families at and after diagnosis, and information is most satisfactory (least harmful) when it provides a sense of hope.(8, 11) Four-fifths of our sample said information on alternative therapies was important, which is unsurprising given up to 95% of individuals with ASDs use these (20) compared to 35% of children not on the spectrum,(21) and further highlights the importance of giving parents evidence-based information on all interventions.

Future research should determine whether giving parents written and spoken information focusing on where to find allied health professionals, how to explain the diagnosis to the child's school, and a tailored therapy plan for the child improves parents' satisfaction with care, engagement in management and degree of distress and adjustment. Furthermore, future research should include an objective measure of clinical practice such as chart review or observation. It is both unrealistic for paediatricians and a potential burden to parents for all aspects of information to be included in a single consultation.

The sheer amount of information discussed at diagnosis can overwhelm parents.(8) Our findings suggest that clinicians should (i) encourage a support person to be present; (ii) provide information about school support, tailored therapy plans and choosing effective therapies either at diagnosis or afterwards; (iii) refer families to allied health professionals;

and (iv) encourage families to explore evidence-based websites. In addition to face-to-face clinical consultations, parents find written information useful, particularly for understanding the diagnosis and explaining it to friends and family.⁽⁸⁾ We thus propose the development of a written information resource kit for parents, which paediatricians can use to guide parents through evidence-based information while managing expectations about the amount of information and services available. Given parents' desires for tailored planning, creating tailored care plans like those for asthma and epilepsy,^(22, 23) which focus on children's individual needs, may reduce parent distress and exposure to harmful information.

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Contributor's Statement: SH, CS and CC conceived the original research questions with revisions by HH. All authors wrote the manuscript. AG, LS and AP had full access to all the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis.

Competing interests: The authors have no competing interest to declare.

What's known on this subject?

- From a parent's perspective, how a diagnosis of autism is conveyed can influence engagement in ongoing intervention.
- From the Australian paediatrician's perspective, the process of diagnosis can be time-consuming and challenging to convey, families are often distressed, and consultation times are limited.
- The agreement or otherwise between parents' information needs and clinicians' practice when diagnosing autism is unknown.

What this study adds:

- Clinicians should encourage a support person to be present at diagnosis and include information about school support, tailored therapy plans and choosing effective therapies.
- Parents' information needs could be met by a written information resource kit, which paediatricians can use to guide parents through available evidence-based information
- Care plans like those that exist for medical conditions, focusing on children's individual needs (particularly strengths) may reduce parent distress and exposure to harmful information.

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Table 1: Characteristics of participating families (N=404)

Child characteristic	Value	Parent/family characteristic	Value
Male, n (%)	344 (85.2)	Birth mother	388 (96.0)
Age (years)		Has a partner	353 (87.6)
Age, mean (SD)	7.1 (2.9)	Age (years), mean (SD)	38.5 (5.6)
Range	2.1 – 16.0	Born in Australia, n (%)	293 (73.6)
Age at diagnosis (years)		Employment status, n (%)	
Age, mean (SD)	5.8 (2.9)	Paid work	218 (54.8)
Range	1.6 – 13.6	Studying full time	12 (3.0)
Diagnosis, n (%)		Not in paid work or study	168 (42.2)
Autism	69 (17.1)	Education, n (%)	
High Functioning Autism	51 (12.6)	Less than high school	56 (14.1)
Asperger's Syndrome	150 (37.1)	Completed high school	67 (16.9)
PDD-NOS	53 (13.1)	Trade certificate, Apprenticeship or Diploma	112 (28.2)
ASD	81 (20.1)	Bachelor degree	108 (27.2)
Educational setting (school/kindergarten), n (%) ^a		Postgraduate degree	54 (13.6)
Mainstream	329 (81.4)	Language spoke at home (English), n (%)	389 (96.3)
Autism specific	33 (8.1)	Annual household income (Aus dollar), n (%)	
For children with various special needs	35 (8.7)	\$29,999 or less	32 (8.2)

Child characteristic	Value	Parent/family characteristic	Value
None	38(9.5)	\$30,000-69,999	97 (24.9)
Aboriginal/Torres Strait Islander descent, n (%)	9 (2.2)	\$70,000-109,999	106 (27.2)
Born in Australia, n (%)	371 (91.8)	\$110,000 or more	99 (25.4)
First-born child, n (%)	221 (54.8)	Missing	56 (14.4)
		SEIFA Disadvantage, n (%)	
		High	147 (36.4)
		Medium	133 (32.9)
		Low	124 (30.7)

^a Some children attended more than one type

Table 2: Parent (N=404) and paediatrician (N=43) report of information resources provided at diagnosis, ranked by importance to families

Information resource	Parent Report N(%)			Paediatrician Report N(%)		Comparison
	Important Yes	Written & Spoken	Not given	Written & spoken	Not given	<i>p</i> value
Finding allied health professionals with autism experience (i.e. a list)	390 (97.7)	89 (22.0)	184 (45.5)	13 (30.2)	10 (23.3)	0.24
What diagnosis means	386 (97.7)	171 (42.3)	23 (5.7)	19 (44.0)	3 (7.0)	0.10
How diagnosis was made	378 (96.7)	205 (50.7)	23 (5.7)	15 (34.9)	3 (7.0)	0.20
Prognosis (what to expect in future)	380 (96.5)	36 (9.0)	156 (38.8)	5 (11.6)	7 (16.3)	0.04
Medicare rebates for therapy	383 (96.0)	104 (25.7)	131 (32.4)	19 (44.2)	4 (9.3)	0.47
Therapy plan tailored to child	376 (95.7)	66 (16.5)	267 (66.6)	6 (14.0)	14 (32.6)	0.08
Choosing effective therapies	379 (95.5)	38 (9.4)	261 (64.8)	5 (11.6)	12 (27.9)	0.24
Understanding allied health	378 (95.0)	89 (22.1)	132 (32.8)	6 (14.0)	7 (16.3)	0.45
Carer's Allowance/payment	378 (95.0)	124 (30.8)	88 (21.8)	16 (37.2)	5 (11.6)	0.31
Details for State Autism Association	371 (93.5)	159 (39.4)	73 (18.1)	19 (44.2)	3 (7.0)	0.15
DSS ^a funding for early intervention	365 (92.9)	128 (31.8)	131 (32.5)	21 (48.8)	4 (9.3)	0.23
About school disability funding	354 (90.5)	34 (8.4)	250 (62.0)	13 (30.2)	6 (14.0)	0.94
Understanding Early Childhood Intervention Services	353 (90.3)	83 (20.6)	156 (38.7)	5 (11.6)	4 (16.3)	0.44

Ways to explain it to school, childcare etc.	351 (89.1)	68 (16.8)	250 (61.9)	8 (18.6)	17 (39.5)	0.65
What child's school can do, or about the Positive Partnerships program	351 (89.1)	21 (5.2)	299 (74.2)	7 (16.3)	23 (53.5)	0.48
Internet sites about autism	352 (88.9)	75 (18.6)	162 (40.2)	15 (34.9)	8 (18.6)	0.42
What causes Autism	342 (88.8)	50 (12.5)	147 (36.7)	6 (13.9)	9 (20.9)	0.62
Choosing school or preschool/ kindergarten	339 (86.5)	10 (2.5)	283 (70.2)	4 (9.3)	18 (41.9)	0.35
Contact details for parent support groups or seminars	339 (85.6)	88 (21.8)	196 (48.5)	11 (25.6)	11 (25.6)	0.04
Books about autism	334 (84.8)	52 (12.9)	237 (58.8)	11 (25.6)	17 (39.5)	0.06
Ways to explain Autism to child	318 (81.3)	22 (5.5)	315 (78.2)	5 (11.6)	20 (46.5)	0.77
Making decisions about alternative therapies	315 (80.0)	12 (2.9)	331 (82.1)	3 (7.0)	21 (48.8)	0.58
Genetics: chance of having a second child with an ASD	297 (75.4)	12 (3.0)	279 (69.1)	1 (2.3)	18 (41.9)	0.40

^aAustralian Department of Social Services "Helping Children With Autism" package

Table 3: Usefulness of sources of information sought by families after diagnosis.

Information source	Useful N (%) ^a
Allied health professionals	319 (83.3)
Other parents/ word of mouth	226 (67.7)
State Autism Association	209 (64.7)
Books	215 (62.1)
Early Days parenting workshop	70 (61.4)
Complementary or alternative therapist	66 (56.4)
Positive Partnership seminar or website	50 (56.2)
Child's paediatrician	212 (55.2)
Other internet sites	170 (53.1)
Raising Children Network website	89 (49.7)
Child and Adolescent Mental Health Services	23 (37.1)
Family doctor	122 (35.9)

^aSample sizes ranged from N=62-384 as not all families used all resources

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